

# State Response to Alzheimer's Disease and Related Dementias

Office of Performance Evaluations  
Idaho Legislature





## Office of Performance Evaluations

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## From the director

November 20, 2020

Members

Joint Legislative Oversight Committee

Idaho Legislature

**Recognizing dementia's negative effects on Idaho families and** the state budget, the Legislature adopted a state plan in 2013 to improve the quality, reach, and coordination of services for people with dementia. But it is now clear that the plan was insufficient on its own. The state did not provide statutory authority, system-wide oversight, and needed resources.

Dementia is a growing public health problem, but Idaho does not have a public health approach as taken in neighboring states that emphasize prevention and early detection. A growing body of research has proven that Idaho could decrease dementia prevalence by addressing risk factors like heart disease and diabetes.

The Legislature should consider developing mechanisms to **oversee, coordinate, and hold accountable Idaho's dementia** response, including the implementation of the state plan. By developing a well-coordinated system of care, the state can **ensure that families don't have to jump through hoops to get the** help they need.

We are grateful to the Department of Health and Welfare, the Commission on Aging, the area agencies on aging, and all the other stakeholders who helped conduct this study. I would also like to thank the service providers who shared their professional and personal stories with us about the challenges of dementia.



Sincerely,

A handwritten signature in blue ink that reads "Rakesh Mohan".

Rakesh Mohan, Director  
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**Formal  
responses from  
the following are  
in the back of the  
report: the  
Governor, the  
Department of  
Health and  
Welfare, the  
Commission on  
Aging, and the  
AAAs.**



**Sasha O’Connell conducted this study, with assistance from Susie Bergeron, Ryan Langrill, Mackenzie Moss, and Emily Pugh Bell. Margaret Campbell copy edited and desktop published the report.**

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# Executive summary



## Why we were asked to do this study

A growing public health issue, dementia refers to a group of symptoms caused by damage to nerve cells in the brain.

**Alzheimer's disease is the most common type of dementia,** accounting for an estimated 60–80 percent of cases.

**About 27,000 Idahoans over 65 years old have Alzheimer's disease,** a figure expected to grow 22 percent in the next five years. **Alzheimer's disease is the sixth leading cause of death in Idaho.** If all types of dementia were ranked as a group, they **would be the state's third leading cause of death, behind cancer and heart disease.**

Although some families have retirement savings, they may not be financially prepared for dementia. The impact of dementia on family resources is profound and greatly increases the likelihood of needing Medicaid. As a result, the impact on state budgets is also profound. **The Alzheimer's Association estimated that** Medicaid payments for Idahoans with dementia were \$144 million in 2019 and will increase to \$194 million by 2025. **Absent any intervention, the state's share of Medicaid dementia costs** would be about \$58 million.

In Idaho, state agencies, nonprofits, and service providers support people with dementia. By coordinating these services, the state could decrease costs and improve quality of life for Idahoans with dementia.

**The Legislature endorsed the Idaho State Plan for Alzheimer's Disease and Related Dementias** and its 11 initiatives to improve dementia care through concurrent resolutions in 2012 and 2013. The plan was led by an informal group of stakeholders called the **Idaho Alzheimer's Planning Group, which has disbanded.** Requesters of this evaluation asked us to review and report on the progress of the plan.



**The Division of Public Health does not have any staff fully dedicated to dementia.**

## What we found and next steps

We found that state agencies play an important role in helping Idahoans with dementia and their family caregivers. Neighboring states have more robust prevention efforts, fewer barriers to service coordination and outreach, and stronger system-wide oversight. Among the recommendations made in this report, the most pressing recommendation focuses on developing ongoing statutory oversight that clarifies stakeholder roles and responsibility for Idaho's dementia response.

### **Idaho does not have a public health response to dementia.**

Mounting research finds some dementia is preventable. A 2020 Lancet Journal commission of medical experts found that 40 percent of dementia cases could be delayed or prevented by addressing 12 modifiable risk factors. Despite potential to reduce dementia prevalence, Idaho does not have a public health response to dementia as it does with other chronic diseases.

**Idaho's death rate for dementia is consistently higher than the national average even when adjusted for its high share of seniors.**

**Idaho's chronic disease programs typically have a full-time** program manager as well as a percentage of time from administrative support staff, a financial specialist, and a section manager. Unlike neighboring states such as Nevada, Utah, and **Washington, Idaho's Division of Public Health does not have any** staff fully dedicated to dementia.

Idaho does not have enough qualified professionals to diagnose and care for people with dementia. Estimates suggest over 60 percent of dementia cases go undiagnosed. In 2019 the state had just 10 geriatricians. Most people with dementia are treated by primary care providers, but 95 percent of Idaho is federally designated as having a shortage in primary care providers.

Dementia education for primary care physicians is a major need. Groups such as Project ECHO and Family Medical Residency of Idaho have taken steps to address dementia training, but stakeholders reported that resources are lacking for comprehensive, ongoing statewide training initiatives.

A dementia program could help primary care providers, caregivers, and the public understand the importance of risk reduction, early detection, and available resources. Early detection can help people with dementia prepare for changes by addressing safety issues in their homes, preparing advance care directives, and making legal plans. With more public education and collaboration, health care providers could help connect Idahoans with community resources.

### **Few family caregivers access support services for Idahoans who want to stay in their home as they age.**

Dementia can reduce the ability to care for oneself independently. Most Idahoans want to stay in their own home as they age, but providing care to them can be challenging. Physical, emotional, and financial stress affect many families, and without adequate support, caregivers often experience health problems of their own.

Supporting family caregivers through services such as training and respite could improve quality of life for Idahoans with dementia and reduce costs of premature entry into an assisted living or nursing facility. But Idaho caregivers often do not access assistance.

**More than 92 percent of Alzheimer's support group leaders who** responded to our survey said living in a rural location poses a barrier to accessing resources and information about dementia. Over eight in ten said not knowing where to start is a barrier for family caregivers.

Idaho does not have enough service providers in some areas. The Commission on Aging is working to increase flexibility so caregivers using subsidized respite services can hire their own providers. Increasing investment to raise provider pay may also address workforce challenges and reduce reliance on more expensive services down the road. A year after Washington increased caregiver support, newly eligible participants were 20 percent less likely to enroll in Medicaid long-term care services.

**Living in a rural location poses a barrier to accessing resources and information about dementia.**

**Our survey found that family caregivers often do not know where to start.**

**Statute treats dementia differently than mental health conditions.**

**Idaho code does not allow involuntary holds for people in behavioral crisis with a primary diagnosis of dementia.**

## **The state lacks emergency options and training standards to stabilize people with dementia in a behavioral crisis.**

Some people with dementia respond to stressful situations with verbal or physical actions that can be disruptive, distressing, or challenging. Training for first responders helps them: (1) identify people with signs of dementia, (2) communicate, and (3) provide appropriate, patient-centered care. First responders have a unique opportunity to connect families to resources. However, they are not usually trained on dementia or available community services.

**Health and Welfare’s Region 4 Mobile Crisis Unit is better** equipped to help than many first responders. The unit supports people with treatment at the scene when possible to avoid unnecessary interaction with jails and hospitals. In July 2020 Health and Welfare expanded this service to all seven regions. Mobile Crisis Unit staff reported that many Idahoans still do not know about the unit and better outreach could help increase access to appropriate care during a crisis.

Idaho code treats dementia differently than mental health conditions. Code does not allow involuntary holds to be placed on people in behavioral crisis with a primary diagnosis of dementia. As a result, a dementia label can keep people from getting the care they need. Without an involuntary hold, people with dementia in crisis may refuse treatment or may be transported to jail. They usually do not receive the care that people with mental health conditions get in similar situations, even though behavioral symptoms are often treatable.

However, expanding the involuntary holds process to include people with dementia could double or triple the number of holds in Idaho, according to an official with the Division of Behavioral Health. Without standards or resources to address involuntary holds, families, communities, jails, and emergency departments are left trying to handle these behavioral crises without authorized treatment for stabilization.

A work group identified necessary changes to Idaho code, but did not propose legislation because a supportive infrastructure is not in place. To address this lack of infrastructure, Idaho could



expand the state hospital system for people with mental health conditions or encourage a private market solution through geriatric psychiatry units at community hospitals. Both options will require ongoing collaboration and accountability across various sectors.

## **Idahoans with dementia face barriers to finding appropriate residential care.**

Many Idahoans with dementia eventually rely on residential care outside of their home. Most people with dementia in residential care facilities have behavioral symptoms. Research shows prevalence of behaviors can be decreased with staff training about topics such as environmental triggers and de-escalation techniques. Staff training is an important component in the safety and happiness of residents. Idaho has lower dementia training requirements for residential care staff than many neighboring states.

In Idaho, direct care staff in nursing facilities must adhere to a federal requirement of becoming certified as a nursing assistant, which includes a training module on dementia. Beyond the initial certification requirement, a state inspection of facilities is meant to identify any weaknesses of staff. Nursing facilities must provide training to address staff weaknesses that come up during the inspection. Staff are not required to undergo training annually nor do they need to have a certain number of hours of dementia-specific training. Half of neighboring states require dementia training for nursing facility staff each year.

Idaho does not require assisted living facility staff to meet a certain number of hours of dementia training, follow a specific training module, or take a dementia competency exam. Nevada, Oregon, Utah, Washington, and Wyoming require a specific number of dementia training hours at onboarding or annually, and some have both.

Stakeholders reported that Idahoans with dementia have trouble finding residential care placement. This lack of placement is due in part to the difficulty in maintaining enough quality staff to manage behavioral symptoms appropriately. Low Medicaid reimbursement also leads providers to prioritize private payers. **Idaho's formula for Medicaid reimbursement likely does not**

**5 out of 6**  
**neighboring**  
**states have**  
**higher dementia**  
**training**  
**standards than**  
**Idaho for**  
**assisted living**  
**facilities.**

**Idahoans with dementia and their caregivers have no single point of contact for information and referral.**

appropriately account for the time assisted living facility staff need to care for someone with cognitive decline.

Without sufficient data, we do not know the scale of placement issues for people with dementia. Health and Welfare staff reported that improving data collection would require collaboration with service providers.

**Idaho has a decentralized dementia response that likely requires more coordination, yet Idaho has less system-wide oversight than neighboring states.**

Idaho has made little progress on its plan to address dementia. The informal group of volunteer stakeholders overseeing the state plan reported that they disbanded because of a lack of organizational capacity and ongoing funding.

Stakeholders consistently pointed to the lack of a governmental entity with responsibility for carrying out the state plan as a reason the plan made minimal progress. Stakeholders with other full-time commitments tried to dedicate time to improving the dementia response system when they could. When available, state agencies applied for and sometimes received short-term federal grants to improve services. Short-term grants may make some gains in supporting Idahoans with dementia, but they do not offer consistent accountability mechanisms and resources. As a result, Idaho struggles to meet its long-term commitments to address the growing number of people with dementia.

Idahoans with dementia and their caregivers have no single point of contact for information and referral. Health and Welfare's 2-1-1 CareLine does not function as a centralized information source for residents with dementia like the 2013 state plan envisioned. Instead, Idaho has multiple information portals with different specialties. Staff differed in their perceptions about the frequency and reasons for one information portal to make referrals to another.

Although stakeholders reported overall good intentions and frequent problem solving to improve communication, our evaluation found Idaho's fragmented system for supporting older adults requires a particularly high level of coordination to prevent people with dementia from slipping through the cracks.

Neighboring states such as Nevada and Utah have aging services housed with other health and welfare services, but Idaho's Commission on Aging is a separate entity. See exhibit 1. Stakeholders reported that this structure prevents Idaho from having the natural flow of communication and resources that may come with being in the same organization. Separation of Health and Welfare and the Commission on Aging also means coordination between the area agencies on aging (AAAs) and public health districts requires relationship building outside the normal scope of work.

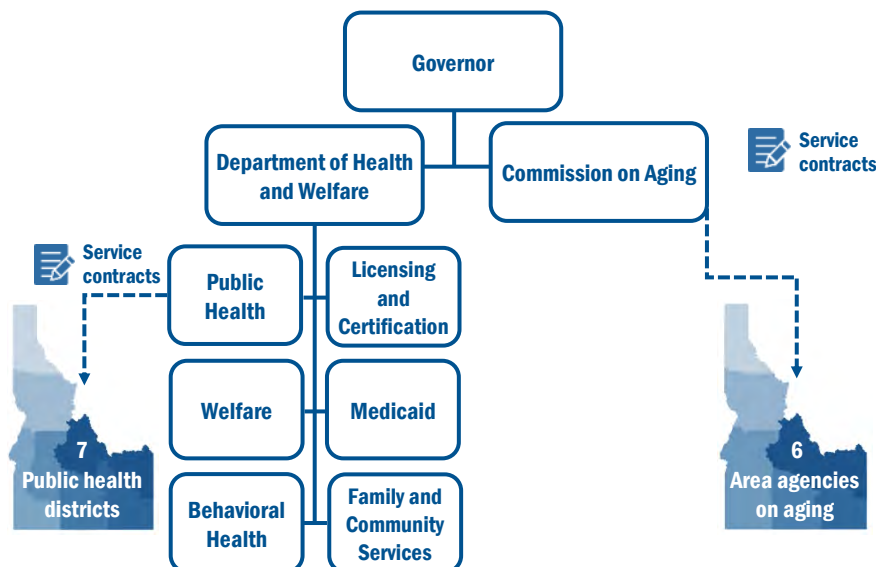
Idaho's AAAs operate separately from the commission. Some AAAs are housed in colleges and others are housed in nonprofits serving low income people of all ages. Compared with other states, Idaho's structure requires more intentional coordination to ensure people with dementia and their caregivers access

**Coordination between the AAAs and public health districts requires relationship building outside the normal scope of work.**

#### Exhibit 1

**The state has several entities providing services to Idahoans with dementia, requiring a particularly high level of coordination.**

Main state agencies and regional contractors providing services to Idahoans with dementia



Note: Public health districts and area agencies on aging are independent organizations that can pursue their own service contracts and grants. This exhibit depicts the primary state agency relationships as they relate to services used by Idahoans with dementia.

Source: Office of Performance Evaluations' simplification based on stakeholder interviews and official organizational charts.

**Every neighboring state has an active task force dedicated to dementia.**



services. Nationally, most AAAs are part of local government entities that provide other services older adults often use, such as senior centers and emergency medical services. AAA staff may know more about outreach opportunities when other services for older adults are provided by the same organization.

Most neighboring states have stronger system-wide oversight for dementia services. Every neighboring state has an active task **force dedicated to dementia. Half of Idaho's neighboring states** have their task force coordinated by a state agency while others **are in the governor's office or are informal.**

Legislatures in Nevada, Utah, and Washington established their task forces in statute. State lawmakers gave clear statutory guidance on task force membership, specifying representation from specific stakeholder groups, including their legislature. These task forces update their legislatures on a quarterly or annual basis. Stakeholders in Nevada, Utah, and Washington reported that their state plan was making progress because their task force and dementia coordinator improved communication and oversight. Neighboring states with informal groups face **similar challenges to that of the Idaho Alzheimer's Planning** Group. Stakeholders in Montana, Oregon, and Wyoming would prefer a more codified oversight system.

## **Policy considerations**

Idaho does not have an ongoing system to oversee, evaluate progress on, or update its state plan to address dementia. Many issues in our evaluation are complicated and involve multiple organizations, requiring a network of supported, engaged stakeholders to address them. Each dementia partner has a role; however, no single stakeholder can do it alone.

We recommend that the Legislature establish a system-wide oversight entity to build on agency efforts, improve collaboration among dementia partners, and ensure ongoing accountability for outcomes. The Legislature could leverage existing agency knowledge by statutorily designating authority and responsibility to establish a dementia task force. The Legislature should consider explicitly stating which sectors would be represented on a task force, how often a state plan should be updated, and when the task force should present state plan progress to appropriate committees or the full Legislature.

Although collaboration is essential, a position ultimately needs to be in charge of driving dementia efforts. Other chronic diseases have a dedicated position in the Division of Public Health at the Department of Health and Welfare. We recommend an ongoing position in Public Health to develop prevention efforts, help drive the dementia task force, and coordinate efforts across the state.

Our evaluation identified steps a task force and dementia **coordinator could consider to further develop Idaho's dementia response**. See page 72, chapter 7. However, none of these steps **would produce an enduring improvement to Idaho's dementia response** without an ongoing structure that ensures collaboration between stakeholders. Statutory oversight can help ensure future dementia efforts do not dwindle.



# 1

## Introduction

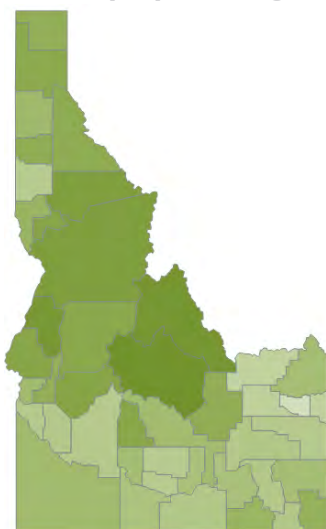
Dementia is a growing public health issue in Idaho. The diseases and conditions that cause dementia slowly destroy brain function, resulting in memory loss, behavioral disorders, and a **decline in functional ability**. **Alzheimer's disease is the most common type of dementia**, accounting for an estimated 60–80 percent of cases.

People over the age of 65 are most at risk for dementia. US Census Bureau data showed this at-risk age group makes up the biggest share of populations in Custer, Lemhi, Adams, Idaho, and Clearwater counties. See exhibit 2.

### Exhibit 2

**Rural Idaho counties have the highest share of people at risk for dementia, while urban counties have the highest number.**

Share of people over age 65



0% 30%

Number of people over age 65



0 61,000

Source: 2018 US Census Bureau population estimates.



The Alzheimer's Association estimated 27,000 Idahoans over 65 years old have the disease, representing 1 in 10 people in this age group. As baby boomers get older and Idaho continues to be a retirement destination, the number of people with Alzheimer's disease is expected to grow 22 percent in the next five years.

Dementia can reduce quality of life and the ability to care for oneself independently. Physical, emotional, and financial stress affect many families and without adequate support, caregivers often experience health problems of their own.

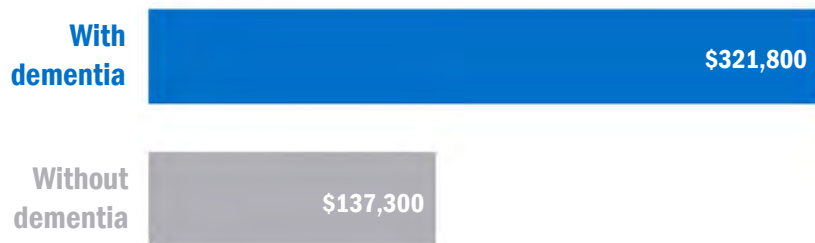
Although some families have retirement savings, they may not be financially prepared for dementia. Nationwide, the average cost of care during the last five years of life is \$184,500 more for a person with dementia.<sup>1</sup> See exhibit 3. Families pay 86 percent of the increased cost through additional caregiving and out-of-pocket expenses. Medicare and Medicaid pay for the balance of increased costs.

As a person's dementia becomes more advanced and their needs increase, families do less caregiving and more costs are paid out-of-pocket or taken on by Medicaid.

#### Exhibit 3

**The average cost of care is \$184,500 more for a person with dementia during the last five years of life.**

Average cost of care during the last five years of life



1. Eric Jutkowitz, Robert L. Kane, Joseph E. Gaugler, Richard F. MacLehose, Bryan Dowd, and Karen M. Kuntz, "Societal and family lifetime cost of dementia: implications for policy," *Journal of the American Geriatrics Society* 65, no. 10 (2017): 2169–2175.

**Alzheimer's disease is the sixth leading cause of death in Idaho.**

**If all types of dementia were ranked as a group, they would be the state's third leading cause of death, behind cancer and heart disease.**

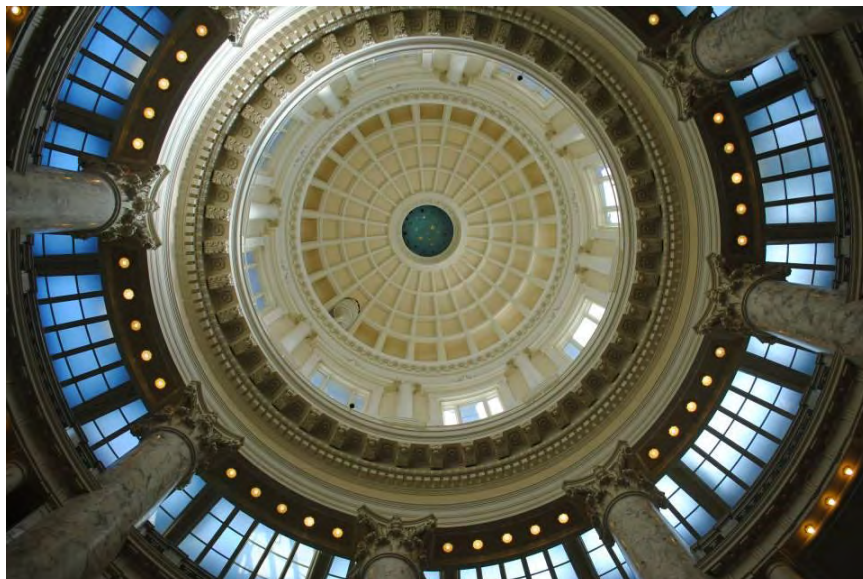
The impact of dementia on state budgets is profound since the high cost of dementia depletes family resources and increases the likelihood of needing Medicaid. People with dementia are more than twice as likely to rely on Medicaid than those without the **diagnosis, according to analysis commissioned by the Alzheimer's Association.** The association estimated Medicaid payments for Idahoans with dementia were \$144 million in 2019 and will increase to \$194 million by 2025. Absent any intervention, the **state's share of Medicaid dementia costs would be about \$58 million.**

## Legislative interest

The Joint Legislative Oversight Committee approved a request during the 2020 legislative session asking us to evaluate the **state's response to dementia.**

Seven lawmakers submitted the request, expressing concern over the projected increase in dementia and its impact on Idaho families. They described challenges in coordinating efforts across several agencies and associated costs to the state. The evaluation request is in appendix A.

**The Legislature endorsed the Idaho State Plan for Alzheimer's Disease and Related Dementias** and its 11 initiatives to improve dementia care through Senate Concurrent Resolution 112 (2012) and House Concurrent Resolution 34 (2013). The requesters asked that we review and report on progress of the plan.



## Evaluation approach

We interviewed stakeholders before developing our evaluation scope. We met with creators of Idaho's 2013 state plan, the Idaho chapter of the nonprofit Alzheimer's Association, and management of the two state agencies most involved in providing services to people with dementia: the Department of Health and Welfare and the Commission on Aging. We examined budgets, statute, regulations, and performance reviews for both agencies. We also searched for relevant legislative studies from all 50 states and reviewed neighboring state plans to address dementia. See appendix B for our evaluation scope and appendix C for our methodology.

# 2

## Coordination and accountability

In 2012 and 2013, the Legislature passed concurrent resolutions endorsing the **Idaho State Plan for Alzheimer’s Disease and Related Dementias**.

The state plan was developed by an informal group of **stakeholders called the Idaho Alzheimer’s Planning Group**. The **Center for the Study of Aging at Boise State University’s College of Health Sciences** conducted a needs assessment for the plan with a grant from AARP Idaho. More than 400 people participated, representing every region of the state. The nonprofit-funded assessment found **Idaho’s most pressing needs** at the time were family caregiver support, centralized information access, and dementia-specific training for providers.

The state plan outlined 11 initiatives to better address the needs of Idahoans with dementia and their families. See appendix D for the initiatives.



## Idaho has made little progress on its plan to address dementia.

We interviewed more than 70 dementia stakeholders in Idaho and neighboring states, including staff supporting Medicaid, emergency medical services, adult protective services, information portals, and residential care. Less than half of the stakeholders we spoke with in Idaho had heard of the state plan before our interview.

**Since the plan's release, state agencies developed a training for caregivers and started collecting more data on dementia:**

The Commission on Aging developed a series of dementia training modules for caregivers in 2019.

In four of the past eight years, Health and Welfare collected information about cognitive health and caregiving through the statewide survey it administers with the Centers for Disease Control and Prevention.

Progress on other goals fell short of completion. As dementia continues to grow in Idaho, older adults still do not have a centralized information portal to access, providers have a patch work of dementia training options with little reach, and family caregivers often do not know about available supports.

Results from an August 2020 Boise State survey of dementia stakeholders complement our interview findings. The survey indicated that stakeholders are often unaware of dementia efforts outside of their own. When asked about progress on the state plan, stakeholders most commonly answered 'not sure' for each initiative.

**Idaho does not have a centralized information portal for dementia.**

**Short-term grants do not offer consistent accountability mechanisms and resources.**

## **No one oversees execution of Idaho's state plan.**

Stakeholders consistently pointed to the fact that a governmental entity was not in charge of carrying out the state plan as a reason the plan made little progress.

**The Idaho Alzheimer's Planning Group oversaw the state plan** without ongoing funding or codification. The group disbanded several years ago, citing lack of organizational capacity and ongoing funding. Idaho does not have an entity or position charged with executing or updating its 2013 state plan.

Stakeholders with other full-time commitments tried to dedicate time to improving the dementia response system when they **could. Since the Idaho Alzheimer's Planning Group disbanded,** ad hoc work groups tried to address regulatory and Medicaid reimbursement challenges facing people with dementia. However, the small groups were unable to fully solve such complex problems without sufficient resources or broad-based buy-in from stakeholders and policymakers, according to participants.

When available, state agencies applied for and sometimes received short-term federal grants to improve services. See appendix F for a list. As an example, a three-year grant funded **the commission's dementia training modules for caregivers and** helped implement a pilot project to increase respite access in southwest Idaho. State agencies were not awarded competitive grants when the funder wanted to target other parts of the **country or when the state's request did not align with funder** priorities. The Division of Public Health recently applied for but did not receive federal funding to develop an infrastructure to respond to dementia.

Short-term grants may make some gains in supporting Idahoans with dementia. But they do not offer consistent accountability mechanisms and resources to help Idaho meet its long-term commitments.

“ Things fall apart, then they get put back together—over and over again. —Commission on Aging staff



## Separation of state agencies requires a particularly high level of coordination to ensure Idahoans with dementia get help.

Two state agencies provide most services for Idahoans with dementia and their families: (1) the Department of Health and Welfare and (2) the Commission on Aging. Health and Welfare has several divisions that oversee many services for people with dementia. For example, it manages health care plans for Idahoans with dementia on Medicaid, oversees standards for residential care facilities, and has contracts with seven regional public health districts offering programs for older adults. It also **manages the state's response to chronic diseases associated with dementia**, and it does some outreach on modifiable risk factors.

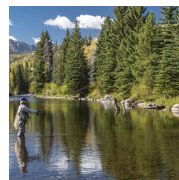
Though these services are offered under one department, Health and Welfare staff reported that internal communication could be improved. For example, Medicaid could inform Licensing and Certification when it approves a new behavioral care unit so this can be accounted for in the survey process. Staff would also like to improve coordination when Licensing and Certification knows about an infraction that will impact Medicaid participants.

Neighboring states such as Utah and Nevada have aging services housed with other health and welfare services. The Commission on Aging is separate from Health and Welfare in Idaho. Stakeholders reported that this structure adds barriers to communication and sharing resources.

The commission helps older adults live at home with support services such as respite, meal delivery, and homemaking. About **80 percent of the commission's appropriation goes to six area agencies on aging (AAAs)** under service contracts.

**Health and Welfare staff reported that internal communication could be improved.**

**An official at the State Independent Living Council reported that the Centers for Independent Living are an untapped resource for dementia. With more coordination of efforts, local centers in communities across Idaho could help connect people with dementia services.**



## **Idahoans must separately apply for AAA services and Medicaid.**

## **Coordinating services between AAAs and public health districts requires relationship building outside of the normal scope of work.**

The commission has a different system than Health and Welfare does for tracking client eligibility and use of services. Several staff at state agencies reported these different systems are a barrier to coordinate services for Idahoans with dementia. For example, a caregiver applying for personal care services through Medicaid may not be informed of support group options available at their local AAA.

**Health and Welfare’s Division of Welfare trains providers on how to help people apply for Medicaid through the department’s IdaLink website;** however, a statewide plan does not exist to ensure AAA staff receive this training. Without a single point of contact, Idahoans must apply for AAA services separately from Medicaid. The separate systems make two processes more difficult: (1) referral of older Idahoans to services for which they may be eligible and (2) prevention of duplicate services.

“ A lot of the time people get shuffled around. We don’t have a very streamlined process for people with dementia.  
—Commission on Aging staff

## **Effect of separation at the local level**

Separation of Health and Welfare and the commission effects how their service contractors coordinate at the local level.

Public health districts have a range of senior services that could offer outreach opportunities for AAAs. For example, the public health district in region 2 recently received a small grant to conduct cognitive health assessments as part of its community health worker program. AAAs could partner with public health districts to connect clients with information about support services for people with dementia following their assessment.

Some AAAs face more barriers to long-term partnerships than others. For more than a decade, the AAA in region 1 has successfully partnered with the Panhandle Health District to provide a senior companion program that includes dementia training. However, several AAAs face high turnover, which can be a barrier to building long-term partnerships if structures to maintain them are not in place. AAA staff told us they would like systems that support communication with local service providers to align efforts, an idea further advocated by an official with the State Independent Living Council.

Stakeholders reported that previous short-term grants funded staff who supported interagency coordination, but funding is no longer available.

### **Staff efforts to communicate**

Health and Welfare, public health districts, the commission, and AAAs try to develop workarounds that increase service coordination. State agencies have developed protocols to share relevant information in certain situations. For example, the Division of Licensing and Certification works with staff from adult protective services when there are allegations of maltreatment in a facility. AAAs call Health and Welfare to find out whether an applicant with dementia is already participating in similar services through Medicaid. Representatives from Medicaid and the AAA must be on the phone simultaneously with the applicant, who is often at home. This extra step requires agencies to invest more time compared with other states that have shared databases, especially when Medicaid phone lines are busy.



## Idaho's AAAs are run by local organizations with different target populations and resources.

Idaho's AAAs operate separately from the commission. Some AAAs are housed in colleges and others are housed in nonprofits serving low income people of all ages. Compared with some **neighboring states, Idaho's structure requires more intentional** coordination to ensure people with dementia and their caregivers access services. The National Association of Area Agencies on Aging reported that most AAAs are part of local government **entities. For example, all of Utah's AAAs are operated by local** government units or associations of local government. Structuring AAAs in local government may centralize services used by people with dementia, such as senior centers and emergency medical services. AAA staff may know more about outreach opportunities when other services for older adults are provided by the same organization.

According to an AAA specialist in Washington, that state moved its AAAs under local government councils after nonprofits struggled to meet grant requirements for federal funding. Staff at the commission reported that some AAAs in Idaho struggle to meet these grant requirements too. Commission staff said that AAAs are sometimes limited in their capacity to quickly meet federal requirements when new funding becomes available for targeted services.

## Idahoans with dementia and their caregivers have no single point of contact for help.

Information about dementia can come from many sources, such as friends, family, medical providers, community groups, or internet searches. All six neighboring states have a public education component in their state plans to improve awareness of dementia services.

In Idaho, the Alzheimer's Association, AAAs, and the 2-1-1 CareLine have free information and referral services to direct people to appropriate services in the community. The three portals have some overlap in the kinds of information they provide, but each also has a distinct and complementary role. AAAs have information and referral specialists available by telephone or in person in each of the six locations. Health and Welfare's 2-1-1 offers free statewide information and referral services through its telephone line and website. The Alzheimer's Association operates a telephone 24/7 Helpline, and the local Idaho chapter provides information and referral during office hours. 2-1-1 only provides information and referral, while AAAs and the Alzheimer's Association offer their own direct services such as caregiver support groups.

The first major recommendation in Idaho's 2013 state plan was to increase public awareness by providing comprehensive, practical, and timely information about the disease and resources available to help address it. To improve information access, the state plan prescribed an initiative to develop and promote a centralized, statewide information portal. The state plan noted that 2-1-1 had already helped fulfill this initiative by becoming a main source for information on Alzheimer's disease.

However, our stakeholder interviews did not confirm that 2-1-1 acted as Idaho's centralized information portal. Instead, we learned caregivers and people with dementia usually do not know where to start and other organizations often act as the first point of contact.

**All six neighboring states have a public education component in their state plans to improve awareness of dementia services.**

**According to survey results, 2-1-1 is not a primary resource for dementia.**

**Cross referrals are important because AAAs and the Alzheimer's Association have different services and expertise.**

When we asked Alzheimer's support group leaders an open-ended question about where they and their members first received information about dementia, none of the survey respondents listed 2-1-1. When we listed several organizations and asked how often their services were used, 64 percent said 2-1-1 is an unused resource.

Through our interviews, we found information portals have different provider lists for services in the community. AAA staff reported that this difference leads to inconsistent referrals depending on where someone starts looking for information. AAA management also said other information portals do not refer people to AAAs enough. Stakeholders raised concerns that families often locate resources too late. We heard several stories of caregivers being frustrated, with some cases leading to neglect or abuse.

“ We hear quite a bit that people wish **they'd known about** us sooner. —AAA staff

## Case study

We developed a case study about a person with signs of dementia and called 2-1-1, **the Alzheimer's Association, and the AAAs for** direction on how to get help. The results of our case study showed no certainty of cross referrals. Staff differed in their perceptions about the frequency and reasons for one information portal to make referrals to another (see appendix E for training and experience of the staff who helped us).

**Cross referrals are important because AAAs and the Alzheimer's Association have different services and expertise. The Alzheimer's Association has knowledge and resources specific to** the disease, including specially trained clinicians. Local AAAs can help families offset the cost of respite, meals, and other services through federal grants. They also have a database of nearby **services that the Alzheimer's Association may not have from its** national partners.

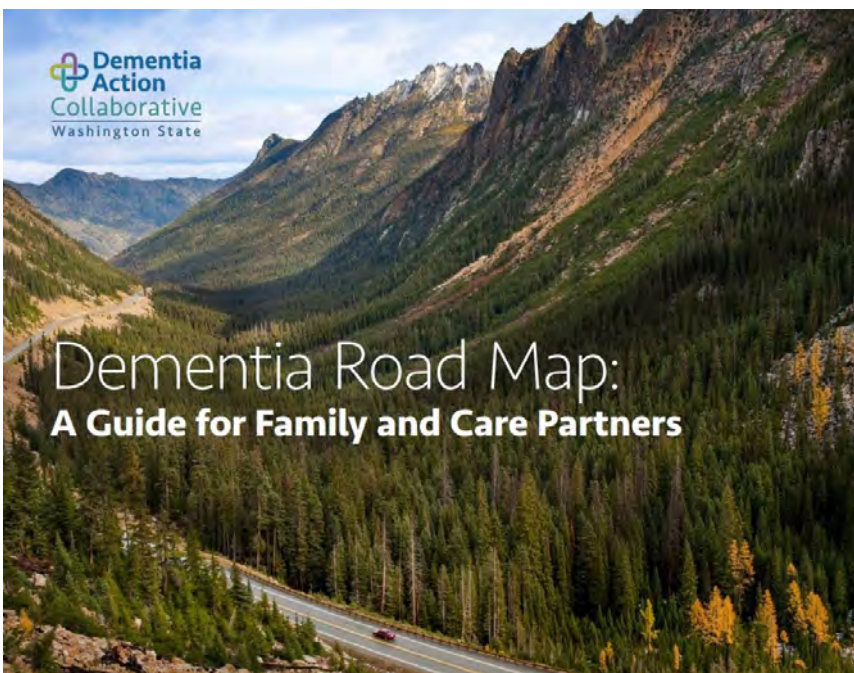
## Road map to services and supports

While reviewing practices in neighboring states, we learned many developed dementia road maps for their residents. The digital and printed pamphlets offer guidance about early diagnosis, what



to expect as dementia progresses, what decisions lie ahead, and available support services. Idaho does not have a dementia road map.

Commission and AAA staff said that they believe a road map would benefit people navigating dementia. The process of developing a road map would require communication among **service providers to best leverage each other's competencies.** Diverse stakeholder engagement would be critical to ensure service providers of all sizes can help connect people across the state to the road map.



**Idaho does not have a dementia road map.**

◀ **Washington's dementia road map**

**Nevada, Utah, and Washington established their dementia task force in a state agency overseeing similar public health and chronic disease issues.**

## **Neighboring states have stronger system-wide oversight for dementia services.**

Idaho has a diverse set of stakeholders working with varied resources in the dementia response system, requiring particularly high levels of coordination to support people with dementia without service gaps or duplication.

Every neighboring state has a task force to improve its response to dementia. **Half of Idaho's neighboring states have their task force coordinated by a state agency while other task forces are in the governor's office or organized as informal groups.**

### **Task forces supported by state agencies**

Nevada, Utah, and Washington have a state agency responsible for managing their dementia task force. Each state also has an agency position dedicated to overseeing the state plan and coordinating efforts to support people with dementia.

Utah lawmakers funded the creation of a state plan in 2011. The Utah Department of Health is statutorily responsible for developing, implementing, and overseeing the state plan. **Plan updates are informed by experts on the Utah Alzheimer's and Related Dementias Coordinating Council. An Alzheimer's state plan specialist helps coordinate and drive dementia efforts.**

In 2013 Nevada lawmakers passed legislation to house the **Task Force on Alzheimer's Disease within the Department of Health and Human Services**. Nevada has two dementia coordinators and statute calls for the Department of Health and Human Services to staff the task force.

In 2014 Washington lawmakers called for the Department of Social and Health Services to convene a task force to develop a state plan. A dementia care program analyst helps drive efforts with part-time support from four staff in other state agencies.

## Task forces supported by governor's offices

Wyoming's task force is organized by the governor's office, which administratively supported the development of its state plan. Dementia stakeholders in Wyoming said they believe involving the legislature more and having a dementia coordinator would have improved the implementation of their state plan. The full group has not met since the plan was released in 2018.

## Informal groups

Oregon's nonprofit-led task force established its state plan in 2012. Stakeholders reported that they are making progress on state plan goals but do not have a formal evaluation process to confirm improvements. The group is now in the process of restructuring. Oregon has state agency staff working on dementia, but the task force is considering recommending a dementia coordinator because they believe the coordinator will help focus efforts on the state plan.

Montana's informal group has had legislative resources and ongoing grant support. Its legislature gave a two-year assignment to the children, families, health, and human services interim committee to study Alzheimer's disease and recommend policy changes while the state plan was being developed. Montana's informal group also has a professional meeting facilitator and administrative support through a grant. However, the grant ends in 2020 and ongoing funding is unclear.

## The legislature's role in neighboring state task forces

Half of Idaho's neighboring states have task forces that were developed with statutory framework from their legislature. These task forces update their legislatures on a quarterly or annual basis. Nevada requires a review process in statute. Its task force must update the state plan biannually and provide an annual report to the legislature and governor by February 1.

The legislature and governor's office are commonly represented in neighboring state task forces alongside key service providers and advocates. See exhibit 4. Lawmakers in Nevada, Utah, and Washington gave clear statutory guidance on task force

**Half of Idaho's neighboring states have task forces that were developed with statutory framework from their legislature.**

membership, specifying representation from certain stakeholder groups, including the legislature.

Stakeholders in Nevada, Utah, and Washington report making progress on their state plan because their task force and dementia coordinator improved communication and oversight. Limited resources and an informal structure led to the Idaho **Alzheimer’s Planning Group disbanding, according to former** group members and other stakeholders. Neighboring states with informal groups face similar challenges. Stakeholders in Montana, Oregon, and Wyoming would prefer a more codified oversight system.

#### Exhibit 4

### **Policymakers, service providers, and the public are commonly represented on neighboring state dementia task forces.**

State policymaker or state agency	Public
Legislators	Health care providers
Governor’s office	Elder law attorneys
Aging services	Residential care providers
Adult protective services	Faith groups
Medicaid	Caregiver advocates
Ombudsman	Disability rights advocates
Disease control and prevention	Senior advocates
Licensing and certification	Alzheimer’s advocates
Minority health	People with dementia and caregivers
Veterans	Researchers
First responders	
Disability services	

Source: Office of Performance Evaluations’ analysis of neighboring state task force membership.

# Prevention and early detection



A small degree of cognitive decline comes with age, but the brain damage associated with dementia is not part of the normal aging process.

**Idaho's dementia death rate is consistently higher than the national average even when adjusted for its high share of seniors.** The state has potential to reduce dementia by modifying risk factors with robust prevention efforts.

Early detection can support quality of life for people with dementia through medical and psychosocial interventions. Getting diagnosed early in the disease progression also helps families prepare for changes and access needed support services.



**The Division of Public Health does not have any staff dedicated to dementia.**

## **Idaho does not have a public health response to dementia like it does for other chronic diseases.**

Many diseases causing dementia have no known cure. None of the medications approved by the Food and Drug Administration **to treat Alzheimer's symptoms can alter the ultimate course of** the disease. Our interviews with experts found that because dementia often does not have a cure, fewer resources may be available despite the potential of interventions to modify risk factors, improve quality of life, and decrease costs.

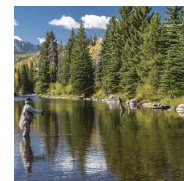
Emphasis on a public health response to dementia is increasing at the national level. In 2011, the Centers for Disease Control and Prevention released a plan to improve cognitive health. Its Healthy Brain Initiative has an action plan for states to improve their response to dementia.

**Idaho's chronic disease programs typically have a full-time** program manager as well as a percentage of time from administrative support staff, a financial specialist, and a section **manager. Unlike Nevada, Utah, and Washington, Idaho's** Division of Public Health does not have any employees fully dedicated to dementia.

The Department of Health and Welfare is uniquely situated to **address dementia prevention. The Division of Public Health's** Bureau of Community and Environmental Health already does public education and outreach for other chronic diseases that share common risk factors with dementia, such as heart disease and diabetes. Neighboring states house their dementia programs with similar agency duties. Health and Welfare is experienced in

**The Healthy Brain Initiative has an action agenda with four domains:**

- 1. Educate and empower**
- 2. Develop policies and mobilize partnerships**
- 3. Ensure a competent workforce**
- 4. Monitor and evaluate**





forging partnerships and promoting public health in communities across Idaho.

Health and Welfare applies for short-term grants when available. It also tries to address dementia with existing resources in two ways: (1) incorporating facts about brain health with other diseases that share common risk factors and (2) engaging in community partnerships to the extent possible.

In the absence of a specific mandate to address dementia, Public Health staff reported that their resources do not support giving dementia the focus that other chronic diseases receive. Nor do resources allow for taking on additional responsibilities of coordinating efforts across various sectors working on dementia outside of Public Health.

Missed opportunities for prevention, early detection, and appropriate care can negatively affect patient outcomes and drive health care costs. Investing in a public health approach to dementia could be cost-effective in addition to helping improve services. **A decrease of even one half of 1 percent in the state's share of Medicaid dementia costs would save Idaho about \$200,000 annually based on Idaho's Medicaid matching requirement and the Alzheimer's Association estimate of costs attributed to dementia.**

**Missed opportunities for prevention, early detection, and appropriate care can negatively affect patient outcomes and drive health care costs.**

**Dementia refers to a group of symptoms caused by damage to nerve cells in the brain.**

## **Behavioral and environmental changes can reduce the risk of dementia.**

Mounting research finds some dementia is preventable. A 2020 commission of medical experts from the Lancet found that 40 percent of dementia cases could be delayed or prevented by addressing 12 modifiable risk factors:<sup>2</sup>

1. Hearing loss
2. Less education
3. Smoking
4. Depression
5. Social isolation
6. Traumatic brain injury
7. Hypertension
8. Physical inactivity
9. Air pollution
10. Alcohol misuse
11. Obesity
12. Diabetes

The risk of dementia can be lowered by building cognitive reserves. Higher educational attainment lowers the risk of dementia. Other evidence suggests reading, speaking a second language, and playing music are associated with maintaining cognitive function. The Lancet commission found hearing impairment may prevent cognitive stimulation but people with hearing impairment who wear their hearing aids have a lower risk of dementia. Being in good physical health can maintain cognitive reserves, allowing the body to handle more brain nerve damage without lowering cognitive ability.

Decreasing damage to the brain and other parts of the nervous system can also lower the risk of dementia. Several modifiable risk factors affect blood flow and inflammation in the brain such as high blood pressure, air pollution, smoking, traumatic brain injury, alcohol misuse, and obesity.

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2. Gill Livingston, Jonathan Huntley, Andrew Sommerlad, David Ames, **Clive Ballard, Sube Banerjee, Carol Brayne, and others, “Dementia prevention, intervention, and care: 2020 report of the Lancet Commission,”** *The Lancet* 396, no. 10248 (2020): 413–446.

## People with dementia often do not get an early diagnosis.

A meta-analysis of several studies estimated that more than 60 percent of dementia cases go undiagnosed in the United States.<sup>3</sup> Washington surveyed more than 2,200 families for its needs assessment and found that people delay getting a dementia diagnosis because of stigma and a sense that nothing can be done.

Idaho lacks data to determine the extent to which and reasons why dementia cases go undiagnosed. The Idaho Hospital Association reported that Idaho does not have enough neuropsychologists trained to administer cognitive evaluations, especially in rural areas. Most people with dementia are diagnosed by their primary care provider. A recent study funded by the National Institutes of Health found that 85 percent of people with dementia are first diagnosed by a provider who is not a dementia specialist.<sup>4</sup>

Medicare has had a cognitive evaluation as part of its annual wellness visit since 2011, yet according to a survey by the **Alzheimer's Association, only 16 percent of adults over 65** reported having their memory and thinking checked. Nine in ten **primary care physicians responding to the association's survey** said it is important to assess all older patients for cognitive impairment, yet less than half said it is their standard protocol to do so.

Often, doctors do not know what type of dementia their patients have. The Bureau of Vital Records and Health Statistics found the type of dementia was not reported for half of Idaho dementia deaths in 2014–2018. Not having an accurate diagnosis may lead to suboptimal care since treatment can vary by type of dementia.

3. Linda Lang, Angela Clifford, Li Wei, Dongmei Zhang, Daryl Leung, **Glenda Augustine, Isaac M. Danat, "Prevalence and determinants of undetected dementia in the community: a systematic literature review and a meta-analysis,"** *BMJ* 7, no. 2 (2017).

4. Emmanuel Fulgence Drabo, Douglas Barthold, Geoffrey Joyce, Patricia Ferido, Helena Chang Chui, and Julie Zissimopoulos, **"Longitudinal analysis of dementia diagnosis and specialty care among racially diverse Medicare beneficiaries,"** *Alzheimer's & Dementia* 15, no. 11 (2019): 1402–1411.

**85%** of people with dementia are first diagnosed by a provider who is not a dementia specialist.

A well-coordinated state dementia program could help primary care providers, caregivers, and the public understand the importance of risk reduction, early detection, and available resources. Early detection can help people with dementia prepare for changes by addressing safety issues in their homes, preparing advance care directives, and making legal plans such as setting up power of attorney. With more public education and collaboration, health care providers could help connect Idahoans with community resources.

## Idaho does not have enough qualified professionals to care for people with dementia.

Professionals who specialize in diagnosing and treating dementia are in short supply, not only in Idaho but also nationwide. Primary care providers help fill the void left by the shortage, but Idaho also has a shortage of primary care providers, particularly in rural areas. Programs to increase the number of providers and help existing providers collaborate remotely may help to resolve some of these challenges.

### Primary care providers

Primary care providers such as physicians and nurse practitioners typically care for people with dementia. A 2020 study by the Idaho Nursing Workforce Center and the Idaho Center for Nursing found that 43 percent of primary care providers are nurse practitioners. Little is known about the scale of Idaho's nurse practitioner shortage.

The Alzheimer's Association's 2019 primary care physician dementia training survey found that four out of five primary care physicians believe they are on the front lines of dementia care. The Center for Health Workforce Studies found that Idaho has fewer primary care physicians per person than most states. In 2016 Idaho had 65 primary care physicians per 100,000 people compared to 75 per 100,000 nationwide, with rural areas hit the hardest.

Family Medicine Residency of Idaho is working to train more family medicine doctors. In 2019 the health education program **was training 55 residents to meet Idaho's need for primary care physicians** and has trained 375 graduates over its 44-year history. Of those, 47 percent have practiced in rural Idaho at some point and 52 percent are still practicing in Idaho. Residents complete four weeks of geriatric medicine rotations, receive lectures in geriatric medicine, and contribute to geriatric referral clinics. The state funded \$3.3 million, or 9 percent, of Family Medicine Residency of Idaho's budget in 2019.

**95%**  
of Idaho was  
federally  
designated as a  
shortage area in  
primary care in  
2019.

**In 2013 Family Medicine Residency of Idaho added a geriatric fellowship program.**

## Geriatricians

The National Center for Health Workforce Analysis reported a growing nationwide shortage of geriatricians. By 2025 the United States will have nearly 27,000 fewer geriatricians than it needs.

**The Alzheimer's Association used these figures to project needs** at the state level. Idaho had 10 geriatricians in 2019. To serve just 10 percent of the expected population over 65 in 2050, Idaho would need 87 geriatricians. However, academic research suggests 30 percent of older adults will need a geriatrician, which would require 261 geriatricians.

Attracting doctors to the field of geriatrics is difficult because geriatric medicine requires specialized training and pays less than other medical specialties. In 2013 Family Medicine Residency of Idaho added a geriatric fellowship program to increase the number of geriatricians in Idaho and raise the level of geriatric training for residents in the family medicine residency program.

## Collaborative care

Access to specialized dementia care is especially difficult in rural Idaho. Service delivery models that allow specialists to collaborate remotely with primary care providers can improve access to health care. A geriatric psychiatrist we spoke with said many physicians in Idaho do not know they can get reimbursed by Medicare for their time collaborating with other health care providers.



The University of Idaho houses an extension for community healthcare outcomes in partnership with other states, known as Project ECHO. Project ECHO is a telehealth program that connects specialists to care teams in rural areas. Around the country, Project ECHO has been shown to improve patient outcomes and reduce health care costs.<sup>5</sup>

Project ECHO also has a continuing education component. In Idaho, Project ECHO has addressed dementia in two modules presented by a geriatric psychiatrist. Stakeholders reported that dementia would be a good fit for Project ECHO continuing education programs, but resources are lacking.

Dementia education for primary care physicians is a major need. Half of primary care physicians do not feel prepared to care for **people with dementia, according to the Alzheimer's Association's** primary care physician dementia training survey.

**The Legislature approved \$200,000 for Project ECHO in fiscal year 2021.**

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5. Angela G. Catic, Melissa L. P. Mattison, Innokentiy Bakaev, Marisa **Morgan, Sara M. Monti, and Lewis Lipsitz**, "ECHO-AGE: an innovative model of geriatric care for long-term care residents with dementia and **behavioral issues**," *Journal of the American Medical Directors Association* 15, no. 12 (2014): 938–942, and Amber B. Moore, J. Elyse Krupp, Alyssa B. Dufour, Mousumi Sircar, Thomas G. Trivison, Alan Abrams, Grace Farris, Melissa LP Mattison, and Lewis A. Lipsitz, "Improving transitions to postacute care for elderly patients using a novel video-conferencing program: ECHO-care transitions," *The American Journal of Medicine* 130, no. 10 (2017): 1199–1204.



# 4

## Family caregivers

A 2019 AARP Idaho survey found that staying in your own home as you get older is very or extremely important to 86 percent of Idahoans over 45 years old.

In 2019, 87,000 caregivers of Idahoans with dementia provided **99 million hours of unpaid care, according to an Alzheimer's Association** analysis of Centers for Disease Control and Prevention and AARP survey findings.

Absent any clinical breakthroughs to cure most types of dementia, support for family caregivers is one way to improve quality of life and reduce costs of premature entry into an assisted living or nursing facility.



## Most Idahoans want to stay in their own home as they age, but caregiving can be challenging without support.

Family caregivers spend time, energy, and financial resources to help loved ones with dementia stay at home. Caregivers assist with housework, shopping, transportation, and managing finances. Eventually many people with dementia rely on caregivers for support with activities of daily living, including getting out of bed, getting dressed, incontinence, bathing, and feeding.

A 2018 AARP survey of more than 1,100 caregivers found that while family members often find caregiving fulfilling, it can also bring financial strain and increased symptoms of depression and anxiety. Academic research supports these findings and documents negative physical health effects for caregivers.<sup>6</sup>

Dementia is particularly challenging for caregivers. Caregivers of people with dementia spend more time taking care of their loved ones than caregivers of those without dementia. Caregivers of people with dementia are also more likely to leave work early, take time off to care for their loved one, and change their work schedule.

Community programs help people to stay at home longer through efforts such as educating caregivers, providing guidance on managing behavioral symptoms of dementia, improving peer connections, and providing respite from caregiving responsibilities. A randomized controlled trial found dementia caregiver support groups and informal consultation delayed residential care facility entry by more than 200 days.<sup>7</sup> Other

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6. Richard Schulz and Lynn M. Martire, "Family caregiving of persons with dementia: prevalence, health effects, and support strategies," *The American Journal of Geriatric Psychiatry* 12, no. 3 (2004): 240–249.

7. Joseph E. Gaugler, Mark Reese, and Mary S. Mittelman, "Effects of the NYU caregiver intervention-adult child on residential care placement," *The Gerontologist* 53, no. 6 (2013): 985–997.

**16%** of Idaho  
Medicaid  
participants with  
dementia live in  
their own home  
or a certified  
family home.

research has found that caregiver training and respite can also delay residential care facility entry by helping better manage behavioral symptoms of dementia.<sup>8</sup>

## Division of Medicaid

Cost and consumer preference have contributed to a national shift from caring for older adults in nursing facilities to more home and community-based care. Nationwide Medicaid spending on home and community-based services surpassed spending on institutional care for the first time in 2013, in part because states shifted more supports to the home with various options and waivers.

**Idaho's Medicaid program provides personal care services,** respite care, cleaning, and other supports that help people with very low incomes safely stay in their homes longer. In 2019, the **average annual cost to Idaho's Medicaid program was \$6,049** for a person receiving support services at home, \$7,665 for someone in an assisted living facility, and \$40,256 for someone in a nursing facility. Despite the lower annual cost of supporting people to live at home, just 16 percent of Idaho Medicaid participants with dementia live in their own home or a certified family home.

State matching requirements for Medicaid depend on average resident income. Idaho must contribute 30 cents per dollar spent on most Medicaid services, while the federal government pays for the rest.

## Commission on Aging

**The Commission on Aging contracts with Idaho's six area** agencies on aging (AAAs). AAAs offer at-home supports for older adults whose income or assets are not low enough to qualify them for Medicaid. Commission staff described these services as helping to decrease Medicaid spending because they delay residential care entry, the high cost of which can drain private resources quickly and lead patients to rely on Medicaid.

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8. Meredith Gresham, Megan Heffernan, and Henry Brodaty, "The Going to Stay at Home program: combining dementia caregiver training and residential respite care," *International Psychogeriatrics* 30, no. 11 (2018): 1697–1706.

Idaho's matching requirements for many services provided by the commission are lower than matching requirements for services provided by Medicaid. Idaho has the same matching rates as other states for commission services offered under the Older Americans Act. The act does not require states to pay any costs for some commission services, such as health promotion or ombudsman services. States contribute 10–25 percent of costs for other commission services, such as congregate meals and caregiver supports.

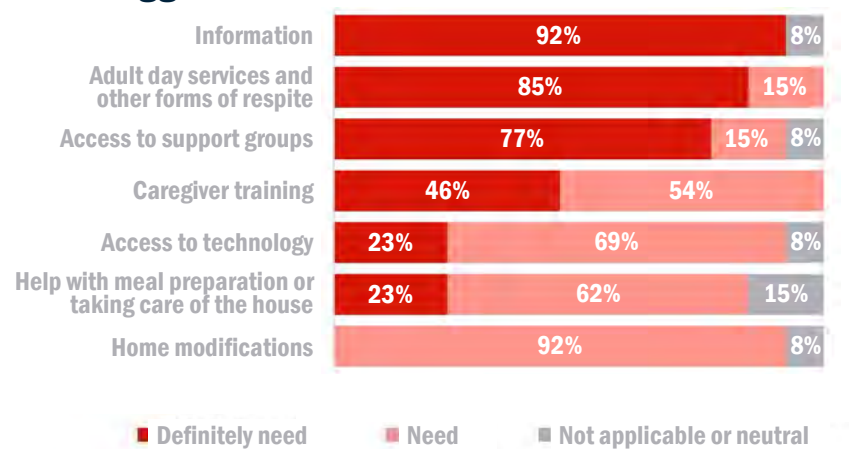


## Idahoans with dementia and their caregivers often do not access available support.

Many of the estimated 87,000 family caregivers of Idahoans with dementia do not know about available at-home supports, according to staff at Medicaid and several AAAs. Data from the commission and Medicaid are limited about how often family caregivers for people with dementia access support services. The commission identified 859 caregivers who received its services last fiscal year. These caregivers reported that their care recipient had moderate to severe memory loss. Medicaid reported that 257 participants with a primary diagnosis of dementia were living in their home or a certified family home at the time of their assessment in 2019. Although these figures are incomplete, they show that many Idahoans with dementia are not accessing at-home supports through Medicaid or their AAAs to ease caregiving responsibilities. Our survey of Alzheimer's support group leaders told us more about service access for caregivers. See exhibit 5.

**Exhibit 5**

### Support group leaders reported that Idaho family caregivers need many resources, but information is the biggest need.



Note: No support group leaders chose 'don't need' or 'definitely don't need' as a response.

Source: Office of Performance Evaluations' survey of Alzheimer's Association support group leaders in Idaho.

All respondents said that dementia caregivers need adult day services and other forms of respite, with 85 percent reporting that respite was a definite need. Ninety-two percent said that access to support groups needed to be improved. All respondents said that dementia caregivers need more training, with 46 percent reporting that training is a definite need. Most believed that dementia caregivers need more support with home modifications, meal preparation, and care of the house.

Our survey demonstrated a need for more public awareness about dementia and available support services. Although support group leaders reported that caregivers need several resources, information stood out as being needed most: 92 percent of respondents said that family caregivers definitely need more information.

When we asked support group leaders about service access, they said not knowing where to start and living in a rural area were barriers for family caregivers to get information and resources about dementia. See exhibit 6.

#### Exhibit 6

### Not knowing where to start and living in a rural area are barriers for Idaho family caregivers to get information and resources about dementia.



**92%** of support group leaders reported that **living in a rural area** is a barrier for caregivers



**85%** of support group leaders reported that **not knowing where to start** is a barrier for caregivers

Source: Office of Performance Evaluations' survey of Alzheimer's Association support group leaders in Idaho.

**All survey respondents said that dementia caregivers need more training.**

**Commission officials reported that low wages contribute to provider shortages.**

## Workforce challenges

Idahoans may not be able to access all services for which they are eligible if providers are not nearby. Staff with the **commission's adult protective services reported times when** they wanted to connect family caregivers in rural areas with respite services, but providers were not available because of low wages. Of the support group leaders responding to our survey:

31 percent reported that they and their support group members are satisfied with the availability of respite care.

23 percent reported that they and their support group members are satisfied with the availability of services for meal preparation and care of the house.

Increasing flexibility may be one way to address workforce challenges. The commission is trying to increase subsidized respite access by helping AAAs develop a consumer-directed service model. AAAs will train caregivers to hire their own respite provider instead of contracting through a home health agency if the caregiver prefers that option.

Increasing state investment in services to raise provider pay may also address workforce challenges. Though the state matching requirement is only 25 cents per dollar invested in AAA caregiver supports, Idaho invested about \$188,000 in 2019, or 28 cents per dollar. Some neighboring states invest at a higher rate with the goal of decreasing facility care costs in their Medicaid budgets. In 2019 Utah invested 33 cents of every dollar dedicated to AAA caregiver supports.

In 2019 Washington invested about 80 cents of every dollar dedicated to its caregiver support program. Washington had established family caregiver supports in 2000, before federal funding was made available through an amendment of the Older Americans Act. A year after Washington increased caregiver support, newly eligible participants were 20 percent less likely to enroll in Medicaid long-term care services.



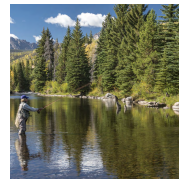
## Adult protective services play a critical role when Idahoans do not get support early enough.

A recent study in the Journal of the American Medical Association found caregiver depression increases the risk of emergency department use for people with dementia by 73 percent.<sup>9</sup> An adult protective services official reported that many cases of maltreatment could be avoided with more caregiver support and education.

The commission recently received a three-year adult protective services expansion project grant to identify and expand on best practices. The project identified service coordination as a need. As a result, adult protective services is now piloting a project to help vulnerable adults and their families build a plan, learn caregiving techniques, and connect with supports such as respite and residential care. Adult protective services staff reported the program has potential to prevent many cases of maltreatment, but funding for the program is unclear after the grant ends in August 2021.

Investigations by adult protective services focus on whether the vulnerable adult was maltreated, not substantiating who committed the act. In our 2019 report, *Southwest Idaho Treatment Center*, we recommended that the Legislature

**The commission's adult protective services helps older Idahoans who may be at risk of abuse, neglect, self-neglect, or exploitation. Adult protective services operates under local AAAs and receives standardized training on dementia from the commission.**



9. Elan L. Guterman, I. Elaine Allen, S. Andrew Josephson, Jennifer J. Merrilees, Sarah Dulaney, Winston Chiong, Kirby Lee, Stephen J. Bonasera, Bruce L. Miller, and Katherine L. Possin, "Association between caregiver depression and emergency department use among patients with dementia," *JAMA Neurology* 76, no. 10 (2019): 1166–1173.

**Idaho does not  
have a  
misconduct  
registry.**

consider establishing a registry of perpetrators of maltreatment so perpetrators could be excluded from working as a caregiver of **vulnerable adults. At the time of our report's release, Health and Welfare and the commission were leading a work group to investigate developing a registry.**

Idaho still does not have a misconduct registry. The work group outlined components necessary to administer a registry and considered advantages of housing the registry under various agencies. An official leading the work group reported that the following factors need to be addressed to move forward with developing a registry. First, a state agency must be charged with operating the registry, including the authority to investigate and take administrative action against the perpetrator. Second, the agency charged with operating the registry must be appropriated staff and funding to properly implement and operate the registry.

## **Idahoans with dementia face more challenges if they do not have family or friends who can help.**

The issue of guardianship came up during several of our interviews, but little is known about how often not having a guardian slows or prevents people with dementia from getting appropriate care.

A guardian has legal authority to care for the personal interests of another person unable to do so. Consistent with Idaho code provisions that require individual autonomy to be preserved to the fullest extent possible, limited guardianship can be tailored to individual needs. Reevaluation is an important part of the guardianship process to ensure autonomy is protected while maintaining safety.

Some people with dementia do not have family or friends able to act as a guardian. Some do not have financial resources to hire a professional guardian or an attorney to set up a guardianship. In these circumstances, a person with dementia could turn to public guardianship.

**A 2007 analysis by the University of Kentucky's Graduate Center for Gerontology** found that states handle public guardianship differently. Social service agencies run guardianship programs in Montana, Utah, and Wyoming. The judicial branch oversees guardianship in Washington. Idaho, Nevada, and Oregon use a county model.

Counties in Idaho are authorized to set up boards of volunteer community guardians, but staff at Health and Welfare and the commission reported that the state does not have enough volunteers. Lack of access to guardianship is most pronounced in rural areas. After reaching out to the American Bar Association, we found that there is little information regarding best practices to ensure enough volunteer guardians. Idaho would need to gather stakeholders to determine its own solution.

**Idaho does not have enough volunteer guardians, and lack of access is most pronounced in rural areas.**

**Not having a guardian when needed can create barriers for placement in residential care.**

Our interviews found complications when people with dementia need a guardian but do not have one. Some first responders are afraid to treat people with limited awareness of their surroundings unless the responders have approval from a guardian. Adult protective services staff reported that without guardianship, people with limited cognitive function may refuse help with food or other needed supports. Staff at the Idaho Supreme Court reported that not having a guardian can create barriers for placement in residential care.

**The commission's client database does not allow AAA staff to** track signs of memory loss unless indicated by a caregiver or guardian. AAA staff reported that this information would help them better target services and ensure people with dementia do not get lost in the system. The commission is exploring ways to collect information about memory loss while protecting privacy.

Policy considerations are in chapter 7.

# Crisis management

## 5

“

I would like to see a lot of light shone on this issue. These are our people and we need to take care of them.

—Official at the Mobile Crisis Unit

Some people with dementia respond to stressful situations with verbal or physical actions that can be disruptive, distressing, or challenging. Caregivers and first responders can avoid or manage behavioral symptoms by addressing the cause of stress. However, they can make behavioral symptoms worse with inappropriate responses. Handling behavioral symptoms of the disease can be difficult and sometimes dangerous for all those involved.

Our interviews with hospitals, residential care providers, and first responders found that instances of severe behavioral crisis in dementia patients are uncommon. However, when severe behavioral crises happen, they are challenging for all concerned. Geriatric experts in Idaho described the experiences of dementia patients receiving crisis intervention in emergency departments and jails as “ghastly” and “a revolving door of inappropriate care.”



**First responders often transport dementia patients in behavioral crisis to hospital emergency or police departments.**

## **First responders often do not receive training on dementia.**

Providers of emergency medical services are often the first responders to people with dementia in behavioral crisis. Without dementia training, first responders may not provide the care that people with dementia need.

Training for first responders helps them: (1) identify people with signs of dementia, (2) communicate, and (3) provide appropriate, patient-centered care. First responders have a unique opportunity to connect families to resources. However, they are not usually trained on dementia or available support services.

First responders often transport dementia patients in behavioral crisis to hospital emergency or police departments. For dementia patients prone to anxiety and confusion, the ambient levels of noise and activity are particularly distressing and may increase behavioral symptoms.

**Health and Welfare’s Bureau of Emergency Medical Services and Preparedness** licenses emergency medical service agencies and personnel. The educational standards for emergency medical services in Idaho are based on national standards that do not address dementia and available support options.

Training that includes dementia could pay off in fewer hospital trips and improved outcomes. Some first responders receive dementia training, but it is limited and not standardized, according to an official with the bureau. Most training efforts are concentrated in Ada County. In rural areas, emergency medical services are often provided by volunteers and the services operate on tight budgets with few resources for training.

“Typically, rural Idaho communities rely on volunteers to staff their EMS agencies. Several of these EMS agencies are challenged to keep enough volunteer responders on the roster to staff an ambulance. —an official with the Bureau of Emergency Medical Services and Preparedness

## The Mobile Crisis Unit is better equipped than other first responders to support people in a behavioral crisis.

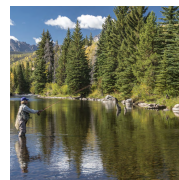
When someone with dementia is experiencing a behavioral crisis, **Health and Welfare's Region 4 Mobile Crisis Unit is better** equipped to help than many first responders. Responders with the Mobile Crisis Unit are licensed masters-level social workers or professional counselors. Most responders with the unit also have a clinical endorsement.

The Mobile Crisis Unit and Ada County Paramedics operate a psychiatric emergency team. The psychiatric emergency team has a paramedic and a clinician from the Mobile Crisis Unit. An official with the Mobile Crisis Unit reported that they often work together with paramedics in cases involving older adults. Paramedics can provide medical clearance to go directly to a psychiatric hospital, avoiding unnecessary and expensive visits to the emergency department.

Region 4 Mobile Crisis Unit responders are trained to handle behavioral symptoms and have some dementia-specific training, though management would like to provide more. Mobile Crisis Unit staff reported that many Idahoans still do not know about the unit, and better outreach could help increase access to appropriate care during a crisis.

**Many Idahoans still do not know about the Mobile Crisis Unit.**

**The Mobile Crisis Unit was initially created 20 years ago in Region 4 and has primarily served Ada County. Its mission is to serve people with dementia or mental health diagnoses in behavioral crisis. When possible, the unit treats people at the scene to avoid unnecessary interaction with jails and hospitals. The unit also follows up with clients after hospitalization, involuntary holds, or other crisis situations. In July 2020, Health and Welfare expanded this service to all seven regions.**





**Statute does not allow involuntary holds for people with a primary diagnosis of dementia.**

**Without an involuntary hold, people with dementia in behavioral crisis may refuse treatment or be transported to jail.**

## **In crisis situations, Idaho code treats dementia differently than it does mental health conditions.**

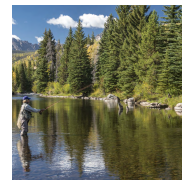
First responders and health care providers we spoke with emphasized that people with dementia in behavioral crisis have wide-ranging care needs. Some can be treated on the scene, others need inpatient hospitalization at a psychiatric hospital for several weeks, while others may get the help they need at a behavioral care unit in a nursing facility. To provide people with behavioral symptoms of dementia appropriate treatment and care, legal and supportive infrastructures need to be in place.

Idaho Code §§ 66-326 and 66-329 allow for temporary involuntary holds to stabilize people with mental health diagnoses. Because dementia is considered a group of neurocognitive disorders and not a mental health condition, code does not allow involuntary holds for people with a primary diagnosis of dementia. As a result, the label of dementia can keep people from getting the care they need. Today families, jails, and emergency departments are left to handle these behavioral crises without authorized treatment for stabilization.

Without an involuntary hold, people with dementia in behavioral crisis may refuse treatment or be transported to jail. First responders must sometimes decide between following the letter of the law or using their professional judgment to place an involuntary hold.

**Law enforcement and certain medical professionals may hold someone involuntarily for psychiatric care if they meet the requirements.**

**After placing the hold, social workers and mental health clinicians authorized as designated examiners assess the patient and recommend to the court whether an involuntary hold is appropriate. Designated examiners recommend psychiatric care when the patient is unable to determine their need for care and is a danger to themselves or others or is gravely disabled.**



## Work group efforts

Idaho code consistently prescribes interventions least restrictive of individual rights and autonomy. If policymakers were to decide to add involuntary holds for people with dementia in behavioral crisis, legislation would be needed. This legislation would have to balance autonomy with the need for appropriate care.

**As part of the Commission on Aging's adult protective services** revitalization project, a work group collaborated with the Office of the Attorney General to draft legislation amending statute for involuntary holds. The work group received the final draft in March 2019.

The draft legislation would add major cognitive disorders, including those that cause dementia, as a class of diagnoses that allows designated medical examiners to place an involuntary hold for treatment. These holds last 24–72 hours. The legislation would make it easier to treat dementia patients who lack capacity to make their own medical decisions yet do not have legal guardianship in place. It would also prevent people with dementia in behavioral crisis from being taken to jail.

Some people need more time to stabilize than allowed under an involuntary hold. Separate legislation would be needed for longer involuntary stays in psychiatric hospitals, which would accommodate the temporary use of antipsychotic drugs. Because nursing facilities have stringent regulations for antipsychotic drugs, psychiatric hospitals can stabilize patients and adjust dosages to levels appropriate for placement in nursing facilities.

**The commission's involuntary hold work group did not** recommend legislation in 2019 because a supportive infrastructure does not exist for people with behavioral symptoms of dementia. In the next section we discuss the kind of support system that would be needed.

**The work group did not recommend legislation because a supportive infrastructure does not exist.**

**Staff with the Division of Behavioral Health guide people with mental health conditions through the involuntary hold process.**

## **Infrastructure does not exist to help with stabilization after a behavioral crisis.**

Expanding the involuntary holds process to include people with **dementia could double or triple Idaho's number of holds**, according to an official with the Division of Behavioral Health.

Through interviews with stakeholders, we identified two main options to accommodate an increase: (1) expand the state hospital system for people with mental health conditions and (2) encourage a private-market solution through geriatric psychiatry units at community hospitals. Both options have barriers that will need to be addressed with ongoing collaboration and accountability across various sectors.

### **Option 1: Expand psychiatric hospitals run by the state**

The Division of Behavioral Health is charged with caring for Idahoans with severe mental health conditions. Health and Welfare leaders reported that they could build off the success of Behavioral Health to support people with dementia going through an involuntary hold process.

Behavioral Health staff act as gatekeepers to guide someone with mental health conditions through an involuntary hold process. For example, Behavioral Health staff do the following:

- Coordinate and oversee two designated examinations and court procedures

- Locate and secure placement in one of two state hospitals

- Coordinate safe transportation from the community psychiatric hospital to the state hospital

- Oversee the state hospital stay, which is 45 days on average for a person with a mental health condition

- Coordinate the release and help find placement in the community

The division does not, however, have enough resources for an influx of people with different diagnoses than it now treats. State hospitals already have waiting lists. According to an official, Behavioral Health is trying to expand the number of beds available for people it now serves. Staff throughout the involuntary hold process also do not have expertise in dementia.

An official with Behavioral Health emphasized that a detailed assessment of resources would be necessary because costs of an expansion are unknown.

## **Option 2: Develop geriatric psychiatry units in community hospitals**

Medicare covers inpatient psychiatric hospital stays for up to 190 **days over the course of someone's lifetime. Although the** emergency department and general psychiatric units at community hospitals often do not have dementia expertise, geriatric psychiatry units are dedicated to treating older patients who require hospital-level assessment and care. Idaho does not have enough geriatric psychiatry units for older adults with behavioral symptoms of dementia.

**Idaho's lack of geriatric psychiatry units is driven by several** factors, according to hospitals and doctors we interviewed. Geriatric psychiatry requires specialized training. Just like the entire field of geriatrics, geriatric psychiatry requires time working with patients and their families, which is not reimbursed at a similar rate of other specialties.

Our interviews with stakeholders also reinforced the need for options to allow longer holds for patients who cannot reach stabilization quickly. Without an involuntary hold policy to support stays long enough to stabilize patients, some geriatric psychiatric hospitals choose not to locate in Idaho. We also heard reports of patients leaving Idaho to receive care at a geriatric psychiatry unit in Utah.

According to the Idaho Hospital Association, a large barrier for hospitals to develop geriatric psychiatry units is the lack of residential care options after an involuntary hold. Without sufficient resources, hospitals could be liable for any damage caused by releasing someone into the community.

**The Division of Behavioral Health does not have the resources and expertise needed to support involuntary holds for people with dementia.**

**Idaho does not have enough geriatric psychiatry units for older adults with behavioral symptoms of dementia.**

**People with dementia struggle to find residential care placement after hospital discharge.**

Discharge planners already report difficulty finding follow-up care for low income dementia patients treated for medical conditions in their emergency departments. As a result, dementia patients sometimes stay in hospitals for weeks or months as a social admit. These patients are cared for by hospitals at unnecessarily high cost, occupying beds intended for acute care patients.

To avoid the costs of housing patients longer than necessary, one Idaho health system has paid for people with dementia to be cared for in residential care facilities in hope that the patient will successfully be enrolled in Medicaid and the health system will be reimbursed. Hospital staff report the frequency of admitting dementia patients because of nonmedical reasons has grown in recent years.

In summary, providers we spoke with reported that community hospitals do not have an incentive to develop geriatric psychiatric services for several reasons:

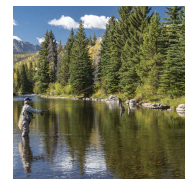
A legal framework is not in place that allows facilities to hold dementia patients in behavioral crisis long enough for appropriate treatment.

The reimbursement system does not adequately compensate for difficult work.

People with dementia struggle to find residential care placement after hospital discharge.

As a result, Idahoans with behavioral symptoms of dementia do not have access to geriatric psychiatric units as they would in other states.

**A patient classified as a social admit is in the hospital for nonmedical reasons. Social admits often have dementia and lack family support and financial resources to pay for residential care. Many of them are not enrolled in Medicaid when they arrive at the hospital, even if they qualify.**



# Residential care

6

This evaluation uses the term residential care to refer to long-term care for adults who stay in a facility other than their home. Nursing facilities offer a high level of care for Idahoans who require 24-hour nursing supervision due to physical or mental conditions. Assisted living facilities serve older Idahoans who are mostly independent but require some support with daily living.

The diseases and conditions that cause dementia are among the most common in residential care facilities. Nationwide, 42 percent of assisted living facility residents and 48 percent of nursing facility residents are diagnosed with dementia, according to the Centers for Disease Control and Prevention.



**Eligible Idahoans can get reimbursed for some caregiving costs by having their home certified through Medicaid. However, few people with dementia use this Medicaid option.**

## **Most Idahoans with dementia who rely on Medicaid live in an assisted living or nursing facility.**

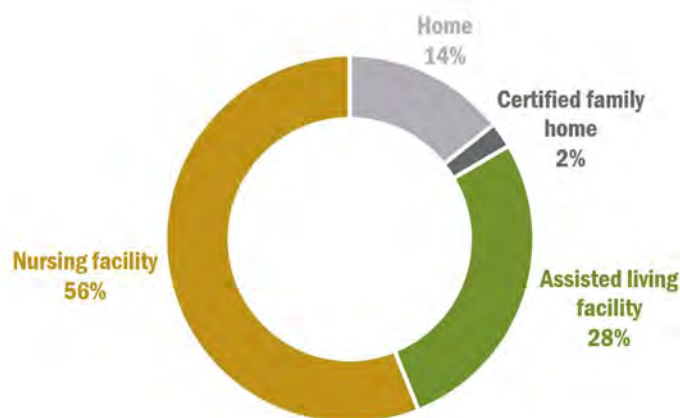
Medicare does not cover ongoing personal care at home, assisted living, or nursing facility visits of more than 100 days. However, Medicaid covers some residential care costs if the participant qualifies.

In Idaho, 84 percent of Medicaid participants with dementia live in an assisted living or nursing facility. See exhibit 7. Medicaid may pay for room and board in nursing facilities but not in assisted living facilities. Residents in assisted living facilities must cover these costs by other means while Medicaid pays for costs to support daily living and medical care. In 2019 Idaho's Medicaid program paid five times more for a month of care in a nursing facility as compared with an assisted living facility.

**Exhibit 7**

### **Idahoans with dementia who rely on Medicaid are twice as likely to live in a nursing facility than an assisted living facility.**

**Medicaid participants with dementia by residence**



Source: Office of Performance Evaluations' analysis of 2019 data from the Department of Health and Welfare.



## Idaho has lower dementia training standards for residential care staff than many neighboring states.

Academic research suggests 56 percent of assisted living and 66 percent of nursing facility residents with dementia have behavioral symptoms with their disease.<sup>10</sup> The Division of Licensing and Certification confirmed many Idahoans in residential care have behavioral symptoms.

Staff training is an important component to keeping residents with dementia safe and happy. Prevalence of behaviors can be decreased when staff are trained in areas such as environmental triggers and de-escalation techniques. Training requirements are an important policy lever for states to ensure staff and resident security.

### Nursing facilities

People with dementia are more likely to live in a nursing facility. One study estimated 75 percent of 80-year-olds with dementia require support from a nursing facility compared with just 4 percent of the general population.<sup>11</sup>

The federal government regulates the ability of a nursing facility to be eligible for payment from Medicaid and Medicare, and state agencies survey nursing facilities for compliance. States also have their own licensing requirements with which all nursing facilities must comply. State regulations can follow federal requirements or exceed them.

10. Malaz Boustani, Sheryl Zimmerman, Christianna S. Williams, Ann L. Gruber-Baldini, Lea Watson, Peter S. Reed, and Philip D. Sloane, **“Characteristics associated with behavioral symptoms related to dementia in long-term care residents.”** *The Gerontologist* 45, suppl. 1 (2005): 56–61.

11. Henry Michael Arrighi, Peter J. Neumann, Ivan M. Lieberburg, and Raymond J. Townsend, **“Lethality of Alzheimer disease and its impact on nursing home placement,”** *Alzheimer Disease and Associated Disorders* 24, no. 1 (2010): 90–95.

**Health and Welfare reported that nursing facility staff often need more hands-on training than they receive.**

Federal standards require direct care staff at nursing facilities to be certified as a nursing assistant within 120 days of employment, which includes a training module on dementia. Then the survey, also known as a facility inspection, identifies weaknesses among staff who stay long enough to be part of the annual process. Nursing facilities must offer training to address staff weaknesses based on their performance evaluation.

Some states exceed federal requirements with additional dementia training before the survey process identifies performance weaknesses. Nevada requires 8 hours of dementia training in the first 30 days of employment and 3 hours annually. Oregon requires certified nursing assistants to complete 3 hours of training quarterly.

Idaho does not exceed federal standards. Nursing facility staff are not required to undergo dementia training annually nor do they need to have a certain number of hours of dementia training. See exhibit 8.

Staff at Health and Welfare said that nursing facility staff need more hands-on training than they receive. Certified nursing assistants often spend just a few hours shadowing someone before they are expected to work independently. To become a certified nursing assistant, just 24 of the 120 required training hours must be on-site at a nursing facility or hospital.

#### Exhibit 8

### Half of Idaho's neighboring states require ongoing dementia training for nursing facility staff.

State	Dementia training required	Competency exams	Initial dementia training hours	Ongoing dementia training hours
ID	-	-	-	-
MT	-	-	-	-
NV	Yes	-	8 hours within 30 days	3 hours annually
OR	Yes	-	Unspecified	3 hours quarterly
UT	-	-	-	-
WA	Yes	-	Unspecified	Unspecified
WY	-	-	-	-

**Note:** Dashes indicate the state does not have an applicable regulation. Some training standards only apply to special care units for people with dementia.

**Source:** Office of Performance Evaluations' analysis of state statutes and regulations.

If facilities do not follow federal regulations, they may face monetary penalties and termination. However, Division of Medicaid staff reported that the federal government does not have strong incentives other than penalties or termination to ensure nursing facilities proactively put available training resources into practice.

## Assisted living facilities

Assisted living facilities can only receive payment from Medicaid if states request this option from the federal government through their state plan or various waivers. Unlike nursing facilities, there are few federal regulations for assisted living facilities. Most states have their own regulations, which vary widely.

Idaho requires assisted living facilities to provide staff with 16 hours of job-related training at onboarding and 8 hours annually after that. The state also requires dementia training for staff at assisted living facilities within 30 days of hire or when someone with dementia moves into the facility. Training must provide an overview of dementia, symptoms of dementia, communication techniques, adjustment to a new living environment, behavior management, activities of daily living, and stress reduction. The Division of Licensing and Certification also offered 11 voluntary behavior management courses in 2017–2019.

We found that most neighboring states have more stringent dementia training requirements for assisted living facilities. See exhibit 9.

For example, assisted living facility staff in Nevada must receive at least two hours of dementia-specific training within a week of employment. Within three months of employment, staff must complete eight hours of dementia training, after which three hours of dementia training is required annually.

Wyoming requires anyone whose wandering poses a health or safety risk to be in a secure dementia unit with staff who receive 12 hours of continuing education on dementia each year. Idaho does not require assisted living facilities to meet a certain number of hours of dementia training or follow a specific training module. Regulations cite the “means and methods of training are at the facility’s discretion.”

**Most neighboring states have higher dementia training standards for assisted living facilities.**

## Exhibit 9

### Most of Idaho's neighboring states require a specific number of dementia training hours for assisted living facility staff.

State	Dementia training required	Competency exams	Initial dementia training hours	Ongoing dementia training hours
ID	Yes	–	Unspecified	Unspecified
MT	Yes	–	Unspecified	Unspecified
NV	Yes	–	2 hours within 40 hours of employment, 8 hours within 3 months of employment for direct care staff	3 hours
OR	Yes	Yes	Unspecified	6 hours
UT	Yes	–	Unspecified	Unspecified for direct care staff, 4 hours for facility administrators
WA	Yes	Yes	8 hours	Unspecified
WY	Yes	–	Unspecified	12 hours for direct care staff, 8 hours for managers

Note: Dashes indicate the state does not have an applicable regulation. Some training standards only apply to special care units for people with dementia.

Source: Office of Performance Evaluations' analysis of state statutes and regulations.

Assisted living facilities may evict residents with behavioral symptoms of dementia. During the Commission on Aging state planning process legal experts raised concerns about how often assisted living facilities evict residents. Although nursing facility evictions are regulated by federal law, residents of assisted living facilities can be evicted more easily because they are subject to landlord-tenant law. The State Ombudsman received 86 complaints about residential care evictions in 2019, a trend which has been increasing on average over the past several years.

State regulations stipulate that assisted living facilities shall not have residents who are a danger to themselves or others, or who engage in behaviors that violate the rights of other residents unless the facility can address them. As a result, Idahoans with certain symptoms of dementia may not be able to reside in an assisted living facility if that facility lacks well-trained staff and effective plans to prevent or manage symptomatic behaviors. Maintaining well-trained staff can be especially problematic in light of the high turnover in facilities.

## **Without sufficient data, we cannot determine the extent to which Idahoans with dementia can access appropriate residential care.**

Since people with dementia are more likely to need Medicaid, barriers for Medicaid participants to access residential care disproportionately impact people with dementia. The state can influence Medicaid costs and services in different ways, such as adjusting reimbursement rates and benefits. Medicaid reimbursement is lower than the market rate for residential care. As a result, residential care facilities often prefer people who can afford to pay privately over those who rely on Medicaid.

### **Behavioral care units in nursing facilities**

Idaho's Medicaid program offers an enhanced reimbursement rate to nursing facilities that designate 20 percent or more of their beds for behavioral care. Facilities must have individualized interventions and weekly behavioral care team meetings to receive the behavioral care unit designation.

Behavioral care units support people with diagnoses that cause cognitive impairment and behaviors that are physically or verbally abusive or socially inappropriate. The division requires an unspecified number of hours in annual training to help facility staff properly serve their target population. Training is not diagnosis-specific but covers management of behavioral symptoms of dementia.

**Behavioral care units are optional in Idaho's Medicaid program.** Training standards are not as wide-reaching as Division of Licensing and Certification standards, which apply to all providers regardless of payment source. Nursing facilities only need to meet behavioral care unit standards if they choose to participate.

In September 2017, the Legislature adjusted regulations to shorten the time frame to qualify for the enhanced rate of a behavioral care unit. Instead of self-funding the first year of operations, the adjustment decreased the cost reporting period

**Nursing facilities must meet behavioral care unit standards only if they choose to participate.**

**More than half of behavioral care unit patients have dementia.**

**Support group leaders reported that Idaho does not have enough behavioral care unit beds available to people with dementia.**

from a full year to 60 days. The number of behavioral care units increased from 6 to 21 following these changes.

More than half of behavioral care unit patients have dementia. The Division of Medicaid and providers are exploring whether to change the minimum share of beds dedicated to behavioral care from 20 to 30 percent, which could further increase residential care access for people with dementia and behavioral symptoms.

We could not determine whether Idaho has enough behavioral care unit beds to meet demand because agencies do not track capacity. Facilities can adjust how many beds are dedicated for behavioral care depending on staffing availability and needs of **other residents. Alzheimer's support group leaders reported that** Idahoans with dementia do not have enough behavioral care unit beds available to them. Just 8 percent of support group leaders who responded to our survey said there are enough beds for private payers, and none said there are enough for Medicaid patients.

Staff from the divisions of Medicaid and Licensing and Certification also reported that Idahoans with dementia have trouble finding placement. Stakeholders reported that two factors contribute to this lack of placement:

Few nursing facilities participate in the behavioral care unit designation.

Behavioral care units face challenges in finding enough quality staff.

Because federal penalties are steep, facilities must be certain they have enough quality staff to serve new and existing residents before admitting a person with behavioral symptoms. Quality staff is important when meeting strict requirements to ensure residents receive only the needed level of medication. Staff must be skilled in interacting safely with residents who have behavioral symptoms.

Staff wages are low, and they often do not stay more than a year. The annual median wage for a nursing assistant in Idaho is \$28,470. Nursing facilities near resort towns compete for staff with higher paying industries in larger cities. Facilities near **Idaho's border see staff leave for higher wages in neighboring states.**

Health and Welfare staff acknowledged that limited resources are a challenge for providers to attract skilled workers. They reported that there should be accountability to ensure facility administrators pass on any potential increase in reimbursement to direct service staff.

“Nursing facilities have a difficult time with nursing staff turnover. Wages are part of the problem, overtime, and undesirable hours. I think other factors include lack of proper education—which extends beyond a PowerPoint or reading a handout. Hands-on training with a staff member of expertise helps substantially. Many times, nurses and CNAs are provided classroom orientation a few shifts shadowing another staff person, and then they are on their own. —Health and Welfare staff

## Secure memory care units in assisted living facilities

In 2019, 37 percent of assisted living facility beds in Idaho were occupied by Medicaid patients. Not all assisted living facilities accept Medicaid, and some require residents to pay privately first. In our 2018 report, *Residential Care*, our survey of assisted living facilities found that 44 percent limit the number of beds available to Medicaid residents and 19 percent reported only accepting Medicaid for residents who paid privately for a certain length of time. Stakeholders reported that this lack of Medicaid-available beds gives some families a tough decision of whether to keep their loved one home longer than they are comfortable with or sending the loved one to a facility farther away from home.

In September 2017, Licensing and Certification developed a designation for assisted living facilities with a secure memory care unit. **Secure memory care units are in 41 percent of Idaho's** assisted living facilities. The units have secure interior and exterior space to make sure residents at risk of wandering do not leave unsupervised.

The units do not have additional facility or training requirements. Similar memory care units in neighboring states require additional dementia-specific training.

Unlike behavioral care units at nursing facilities, secure memory care units do not receive an enhanced Medicaid reimbursement. In comparison, assisted living facilities in neighboring states

**Not all assisted living facilities accept Medicaid, and some require residents to pay privately first.**



**Stakeholders reported that Idahoans with dementia who can afford to pay privately have better access to secure memory care units than those with Medicaid.**

offer a flat supplemental reimbursement. For example, Oregon has a supplemental reimbursement of \$570 per month for each resident with dementia.

Though Medicaid does not reimburse more for secure memory care unit beds, the private market sets a higher price for them. Secure memory care unit beds usually cost \$1,000 more per month than a standard assisted living facility bed, according to the Idaho Health Care Association.

Data are not available on the number of beds in secure memory care units that go to Medicaid patients, but staff at Health and Welfare reported that beds go disproportionately to private payers.

**When we asked Alzheimer’s support group leaders about bed availability by payor type, 62 percent reported that there are enough secure memory care unit beds available for private payers. None of the support group leaders who responded to our survey said there are enough secure memory care unit beds for Idahoans on Medicaid.**

## Medicaid likely does not accurately reimburse assisted living facilities for time needed to care for residents with dementia.

Medicaid reimburses assisted living facilities based on the level of care needed by residents, but Idaho may not be appropriately accounting for the staff time needed to care for residents with cognitive decline.

Nurses from the Division of Medicaid use a uniform assessment instrument to score a resident's necessary support for eating, bathing, supervision, and other functional areas. Medicaid then determines standardized time allocations based on the resident's need scores and a study of how long it takes staff to care for residents. This standardized time allocation is used to determine a daily reimbursement rate to the provider. See exhibit 10.

A work group led by Health and Welfare found that the standardized time allocation likely does not account for the full amount of time staff need to supervise residents with dementia or other cognitive limitations. Although the uniform assessment instrument appears to score resident needs appropriately, results of the staff time study may lead to inadequate reimbursement. The staff time study was conducted in a nursing facility in 2000.

Assisted living facilities may be losing \$50 per day by accepting a dementia patient. While the workgroup's findings supported concerns raised by assisted living facilities, it had a small sample size due to limited resources and provider participation. The workgroup recommends a formal time study be administered before making any changes.

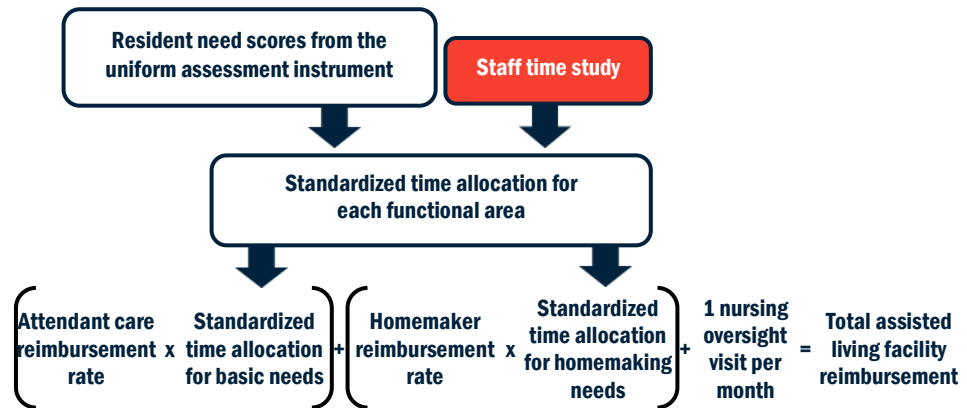
Appropriately reimbursing assisted living facilities for time to supervise and care for residents with dementia may increase the number of providers willing to accept Medicaid. By better accounting for the individual needs of the resident, stakeholders reported that residential care access for people with mental health conditions would also increase. Adjusting the formula may also help improve workforce dementia capability if higher reimbursements are used to increase training and pay for direct service providers.

**Assisted living facilities may be losing \$50 per day by accepting a dementia patient with Medicaid.**

## Exhibit 10

**An inadequate formula for **staff time** to care for dementia patients may be reducing provider Medicaid reimbursement and contributing to fewer residential care beds.**

Medicaid reimbursement formula for assisted living facilities



Source: Office of Performance Evaluations' simplification based on information from the Division of Medicaid.

Idaho could build on its endorsement for secure memory care units by offering a higher Medicaid reimbursement for facilities with staff who go through additional dementia training. However, stakeholders reported adjusting the uniform assessment instrument may be more straight forward than setting up a new type of license. Staff at the Division of Licensing and Certification believe their surveying process is sufficient to ensure appropriate quality of care and updating the tool could increase assisted living facility access for Idahoans with dementia who rely on Medicaid.

# Policy considerations



Idaho does not have a system to oversee, evaluate progress on, and update its state plan to address dementia. Many of the issues discovered through our evaluation are complicated and impact multiple organizations, requiring a network of supported and engaged stakeholders to address them.

## **Idaho's dementia response needs a system-wide oversight entity.**

The Legislature should consider establishing a system-wide oversight entity to build on agency efforts, improve collaboration among dementia partners, and ensure ongoing accountability for outcomes.

The Legislature could leverage existing agency knowledge by statutorily designating an agency the authority and responsibility to establish a dementia task force. To help ensure one issue or region does not drive the agenda, the Legislature could develop statutory membership guidelines that include key stakeholder groups across the state. Requiring annual progress reports to the **Legislature and the Governor's Office** would help ensure appropriate oversight.

## **The state should dedicate a position to drive dementia efforts.**

Although collaboration is essential, a position ultimately needs to be in charge of driving dementia efforts. Other chronic diseases have a dedicated position in the Department of Health and **Welfare's Division of Public Health**. **Neighboring states with a dementia coordinator** report progress on their state plans because of the position. We recommend an ongoing position in the Division of Public Health to develop prevention efforts, help drive the dementia task force, and improve coordination across the state.

**Each dementia partner has a role; however, no single stakeholder can do it alone.**

## **We identified steps for a task force and dementia coordinator to consider.**

A statutorily designated task force and an ongoing position dedicated to coordinating dementia efforts could provide an infrastructure to make enduring improvements for Idahoans with dementia and their families. We identified the following steps to further develop Idaho's dementia response.

### **Prevention and early detection**

Increase outreach to decrease stigma, improve awareness of modifiable risk factors, and emphasize importance of early detection

Promote existing programs and explore new opportunities to train primary care providers and specialists who can diagnose and treat dementia

Work with healthcare groups to set standards for workforce training specific to dementia and expand existing programs such as Project ECHO to include ongoing modules that reach rural communities

Expand primary care provider knowledge of Medicare reimbursement for collaboration and cognitive assessments

Increase collaboration with care providers to connect patients with resources and information after diagnosis

Develop a plan to encourage partnerships among AAAs, public health districts, and other local service providers to connect older adults with information about support services

### **Family caregivers**

Increase public awareness of caregiver support services

Improve consistency in cross referrals among information portals by developing a statewide plan for collaboration

Leverage the existing IdaLink website by training AAAs on how to help older adults apply for eligible services through Health and Welfare

Improve sharing and vetting of information portal resource lists for community referrals

Examine ways to expand the caregiver support workforce

Expand prevention efforts of adult protective services

Develop a dementia roadmap for Idahoans to learn about what should be done at various stages of their disease and where to go for support

## **Crisis management**

### **Work with Health and Welfare's Bureau of Emergency**

Medical Services and Preparedness to develop protocols for caring for dementia patients in crisis and distribute the protocols to first responders statewide

Develop protocols for families who call for emergency assistance to receive information about available supports

Increase public awareness of Mobile Crisis Unit

Evaluate infrastructure needed to expand state psychiatric hospitals and barriers to the development of geriatric psychiatry units in community hospitals

## **Residential care**

Formally assess and adjust the Medicaid reimbursement formula for assisted living facilities to appropriately account for cognitive decline

Work with the Division of Medicaid and nursing facilities to develop a mechanism that tracks bed capacity at behavioral care units

Examine feasibility and barriers to having a minimum number of hours for dementia training for residential care staff

Develop mechanism to track bed use by payor type at secure memory care units

Scientific evidence is mounting on the potential to prevent or delay dementia. A public health approach can help ensure dementia is given attention like any other chronic disease. The **state's fragmented system requires ongoing collaboration among** stakeholders to ensure Idahoans have their needs met at all stages of disease progression. Statutory oversight can help ensure future dementia efforts do not dwindle.



# Request for evaluation





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#### COMMITTEES

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## Idaho State Senate

### SENATOR MARK R. HARRIS

Joint Legislative Oversight Committee  
Co-Chair Senator Mark Harris  
Co-Chair Representative Llana Rubel

Dear Joint Legislative Oversight Committee.

Today, an estimated 5.6 million Americans aged 65 and older are living with Alzheimer's disease. By 2050, there are projected to be nearly a million new cases every year. To date, more than 26,000 Idahoans are living with Alzheimer's and other dementia related disease. This figure is expected to increase to over 33,000 by 2025. According to the Centers for Disease Control, Alzheimer's is the sixth leading cause of death for Idahoans.

Caring for people with Alzheimer's in Idaho is projected to cost Medicaid \$144 million in 2019. By 2025, this number is expected to increase by 34.7%. Medical bills are 23 times higher for people with Alzheimer's and other dementia covered by Medicaid and Medicare than people without Alzheimer's and other dementia also on Medicaid and Medicare.

Alzheimer's is a devastating disease, but its impact is not just on those with the disease. Alzheimer's affects entire families, causing financial hardships. To date, there are more than 85,000 caregivers in Idaho giving hours of voluntary care.

Numerous state agencies administer a variety of programs critical to people with dementia, such as respite care, nutritional care, and public health. Additional critical state efforts include regulatory oversight pertaining to the licensure of care facilities, enforcement of training requirements, and elder abuse protections. Local law enforcement are often first responders to crisis experienced by those with dementia. Unfortunately, these efforts are often siloed with multiple state agencies each working separately from one another. This lack of coordination hinders the ability of Idaho to evaluate the effectiveness of policy efforts across the spectrums of programs serving those with Alzheimer's and their families. This in turn makes it more difficult for the state to keep a strategic Alzheimer's State plan updated, executed and relevant to the change in health care.

We request that OPE study and make recommendations in the following five areas.

Study Idaho agency coordination of efforts to address the increases in Alzheimer's disease and other dementias that lie ahead. Identify mechanisms whereby state actions can be centrally coordinated and overseen.

Identify gaps and needs within state agencies as well as any potential cost savings that may be realized by eliminating duplicity.

Review and report on the progress of the Idaho State Alzheimer's Plan, endorsed by the legislature in HCR 34 in 2013.

Provide information concerning the infrastructure Idaho has in place regarding programs, services, regulations and laws addressing Alzheimer's disease and other dementia and their effectiveness.

Explore ways in which Idaho can limit the impact of Alzheimer's disease and other dementia long-term on Idaho's budget, patients, caregivers, and healthcare systems by building on successful chronic disease programs in Idaho and on Alzheimer's disease and related dementia programs in neighboring states.

The study would be a significant step in articulating the state's commitment to policies and actions that support its citizens affected by the disease and preparing the state for the enormous increases in Alzheimer's disease and other dementia that lie ahead.

Thank you for your consideration.

Sincerely,



Senator Mark Harris



Representative Rick D. Youngblood



Senator Cherie Buckner-Webb



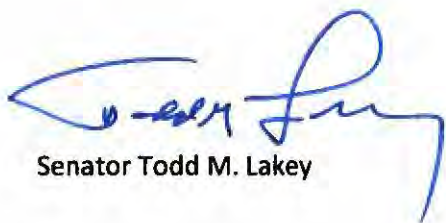
Representative Sage Dixon



Senator Michelle Stennett



Representative Linda Hartgen



Senator Todd M. Lakey



## Evaluation scope

1. Discuss Idaho's infrastructure for addressing dementia.
2. Assess how well state and nonstate entities coordinate dementia efforts.
3. Identify any service gaps that might exist for dementia.
4. Identify any lessons that Idaho can learn from neighboring states to address the challenges of dementia.

# Methodology



## Data limitations

Dementia often goes undiagnosed. The diseases and conditions that cause dementia also often occur with other issues that may be marked as a primary diagnosis in medical records.

Diagnosis-specific data on service use and costs are limited. Not all agencies that provide services to Idahoans with dementia have access to medical records and some data systems only track services by need rather than diagnosis. For example, the Commission on Aging does not collect information about diagnoses and only tracks memory loss under certain conditions. The Division of Medicaid does not have claims by diagnoses for home and community-based services, which include all at-home services and assisted living facilities. The Division of Licensing and Certification knows the share of assisted living facility residents with dementia, but not the share in nursing facilities.

We addressed data limitations with a mixed methods approach. Improved data collection about service use would better inform future evaluation efforts.

## Literature review

Our evaluation relied in part on academic research about dementia prevalence, costs, and best practices. We reviewed medical journals and studies funded by states, the federal government, and nonprofit organizations. Our search focused on the following areas:

- Prevalence and modifiable risk factors of dementia

- Long-term care costs of dementia for families, Medicare, and Medicaid



**We conducted  
more than 70  
interviews with  
diverse  
stakeholders.**

Health and financial effects of caregiving

Effectiveness of caregiver interventions to safely delay  
residential care

Prevalence and effectiveness of training to mitigate  
behavioral symptoms of dementia

## Interviews

Our primary method of understanding the status of collaboration and service gaps was stakeholder interviews. Idaho has a diverse set of agencies, nonprofits, and service providers supporting people with dementia. We conducted more than 70 interviews which included people from the following agencies or in the following roles:

- Department of Health and Welfare
  - Division of Behavioral Health
  - Division of Family and Community Services
  - Division of Licensing and Certification
  - Division of Medicaid
  - Division of Public Health
  - Division of Welfare
- Commission on Aging
- Area agencies on aging (AAAs)
- State Independent Living Council
- Idaho Supreme Court
- Emergency response
- Hospital systems
- Personal assistance
- Home health care
- Geriatric psychiatry
- Residential care
- Dementia response systems in all six neighboring states

Most interviews were an hour long with follow-up questions in writing. The questions were open-ended and varied depending on stakeholder expertise. All interviewees in Idaho were asked about coordination of dementia services and status of the 2013 state plan to address dementia.

## Survey of caregiver support group leaders

Family caregivers play an important role in Idaho's dementia response. We were initially going to hold focus groups with caregivers, but we decided not to meet with caregivers in person because of the COVID-19 pandemic.

We consulted with Boise State University's Center for the Study of Aging, the Idaho Caregiver Alliance, the Alzheimer's Association, and AARP Idaho about how to get more information about the experience of caregivers. We learned from stakeholders that caregivers often have low survey response rates, but support group leaders offer a valuable perspective.

We surveyed Alzheimer's Association caregiver support group leaders across Idaho about dementia service needs, access, and use. The Alzheimer's Association operates Idaho's largest network of support groups for caregivers of people with dementia. They work with 240 Idaho families who navigate the disease each year, and they have often been caregivers themselves. Nineteen of the 38 Alzheimer's Association support group leaders responded to our survey, representing caregivers across 10 counties:

Ada	Custer
Bingham	Gem
Bonner	Jefferson
Bonneville	Kootenai
Canyon	Payette

Staff from the Alzheimer's Association reviewed our survey to ensure suitability for the population.

The survey was open for two weeks in August 2020 and two reminders were sent over that time. Questions used Likert response options to indicate the intensity of agreement or disagreement. All questions had neutral and not applicable response options. Space at the bottom of each section and at the end of the survey was reserved for any open-ended comments.

See appendix E for details on our case study.

**50%** of support group leaders responded to our survey.



# Status of the state plan

State plan initiative	Status	Stakeholders reporting 'no progress' or 'not sure'
"Develop and promote a centralized, statewide information portal about Alzheimer's and related dementia."	2-1-1, AAAs, and the Alzheimer's Association act as separate points of contact and provide different resources with varied cross referral.	48%
"Develop and implement a statewide Alzheimer's and related dementia education program using continuing education credits for health care professionals, including physicians, nurses, social workers, pharmacists, etc."	There are training opportunities for providers, such as the Commission on Aging's dementia training for caregivers and Licensing and Certification's behavior management training. No statewide, cross industry, continuing education plan exists.	65%
"Promote existing professional and lay caregiver training programs."	Powerful Tools for Caregivers is on the 2-1-1 website, which meets part of the initiative description. The planning group no longer exists and cannot support training promotion.	36%
"Develop and promote geriatric-centered curricula for students pursuing health care careers."	Some opportunities exist for health care students to focus on geriatrics, such as a fellowship program and options to minor in aging studies or gerontology. The planning group has been unable to promote programs since disbanding and cannot support new program development.	66%
"Work with industry trade groups to provide additional, standardized Alzheimer's and related dementia training for institutional and home-based professional caregivers."	The Commission on Aging developed a series of dementia training modules for caregivers. The commission is unable to track the number of participants, but voluntary participant surveys will be summarized in the commission's annual report.	46%
"Promote and develop a community-based 'resource counselor' or 'care coach' program using trained lay people to shepherd newcomers through the Alzheimer's and related dementia landscape."	Idaho Caregiver Alliance recently received a short-term grant to start a family caregiver navigation pilot in southwest Idaho. No statewide navigation program exists for caregivers of people with dementia.	61%
"Link current Alzheimer's and related dementia support groups and respite care services into a vetted caregiver support network and provide viable options for areas of the state not presently served (i.e., rural areas)."	Idaho Caregiver Alliance reaches a small portion of caregivers. Respite and support group options remain limited for rural areas.	53%

## State Response to Alzheimer's Disease and Related Dementias

State plan initiative	Status	Stakeholders reporting 'no progress' or 'not sure'
"Establish a consortium of institutional care providers and advocates to propose regulatory reforms regarding such matters as staffing ratios, training standards, and Medicare/Medicaid reimbursement rates related to the treatment of Alzheimer's and related dementia."	Short-term work groups came together for temporary grants. No ongoing consortium was developed.	68%
"Provide financial incentives (e.g. tax credits or deductions) to help family members keep loved ones with Alzheimer's and related dementia at home longer before institutionalizing them and thus reducing Medicaid outlays."	No applicable state tax credits or deductions have been created since the state plan was released.	82%
"Work with the Department of Health and Welfare to incorporate questions about cognitive health into their annual Behavioral Risk Factor Surveillance System (BRFSS)."	Cognitive health and caregiving modules were incorporated into the BRFSS survey with financial support from the Alzheimer's Association and the Legislature in 2013, 2015, 2016, and 2020. Although ongoing funding is unclear, the Division of Public Health would like to administer modules in alternating years moving forward.	75%
"Create an annual mechanism for reporting progress to the legislative and/or executive branch of the state government."	No annual reporting mechanism exists for the state plan.	68%

Source: Office of Performance Evaluations' interviews and a 2020 survey of 29 dementia stakeholders by Boise State University.





## Case study

We developed a case study approach to learn about information Idahoans receive when first accessing support. We asked information and referral experts from Oregon and Washington for input on the scenario and received confirmation from AAAs specialists that our case study described a common call.

We asked information and referral specialists at the 2-1-1 **CareLine, the local and national Alzheimer's Association, and all six AAAs** how they would respond to a caller with this scenario:

**A person's mother lives alone in another town and is having** evident memory problems. The mother forgets to do things; has trouble cooking, including burning food and remembering to take medications or the correct dosages. There are no immediate issues related to nutrition, housing, or medical conditions, but the memory problem could bring such issues to the fore. There are also no financial problems. The main concern is one of safety. The mother is aware that there are memory problems and is worried about them. The mother is 75 years old and is on Medicare. She has not seen the doctor for over a year. The person calling wants to know what to do.

Leading sources such as the National Institute on Aging emphasize the importance of getting an early diagnosis when memory loss starts to become a problem. Therefore, we expected an information and referral specialist would suggest seeking a diagnosis and would probe more to learn about the situation. Because the case study scenario presented potential safety concerns, we expected that either 2-1-1 **and the Alzheimer's Association** would make a referral to a local AAA for support from its adult protective services program.

## 2-1-1 CareLine

Someone using the search function of the 2-1-1 website would not be able to present the case study scenario. However, they could **try to find information on memory loss, dementia, or Alzheimer's** disease by using those terms as search prompts.

We searched for information on memory loss, dementia, and **Alzheimer's disease among the 15 community resource search** headings. There was a category dedicated to caregiver resources, but it was not functioning. The search of key words also did not produce any results in the categories of medical/health care or mental health.

The advanced search engine did not produce results for memory loss but did bring up relevant information with the search terms **dementia and Alzheimer's. Most of the references for Alzheimer's were to local Idaho chapters of the Alzheimer's Association and** none were to an AAA. The results for dementia were more **extensive, providing references to the Alzheimer's Association** programs and to all six AAAs. 2-1-1 is open to working with the Commission on Aging to find ways to ensure that searches **relevant to memory loss, dementia, and Alzheimer's** would produce the right kind of referrals.

Although the search functions do not consistently pull up main resources available to people with dementia, 2-1-1 highlights key services for caregivers on its home page. The caregiver home page link has information on respite options, reimbursement for caregiving, and other resources including an AARP Idaho guide to caregiving.

We interviewed 2-1-1 staff to learn about the caller experience. Although the staff and the caller access the same database, the 2-1-1 staff can use their experience and judgment to refer the caller to needed services. The 2-1-1 information and referral person we spoke with had 12 years of experience but no specific training on dementia. In responding to the case study scenario, **she would refer general memory loss questions to the Alzheimer's** Association 24/7 Helpline; but if the issue involved safety, she would refer the caller to the local AAA. These responses met our criterion for directing a person to the appropriate source for help.

## AAAs

We interviewed an information and referral specialist at each of the six AAAs. Their experience on the job ranged from 7 months to 13 years. Their training varied widely, from certification from the Alliance for Information Referral Systems, to on-the-job training, to no specific training yet. Most specialists received dementia training from the commission and two specialists **mentioned other training from the Alzheimer’s Association and a university course.** The commission recently developed dementia-capable training for information and referral specialists with funding from a short-term grant. The training will likely be available to AAA staff by the end of 2020.

Despite the diversity in experience and training, all the specialists gave helpful responses to the case study scenario. All six said they would recommend to the caller that the parent see a doctor, get an assessment, or receive a diagnosis. The specialists focused on learning more about what was causing the memory loss and what next steps would be appropriate. Safety was a high priority for the specialists, and some mentioned the possibility of **requesting support from the AAA’s adult protective services.** The specialists described several possible interventions and caregiver support services.

AAAs reported that most of their dementia referrals come from **doctors’ offices, senior centers, friends, family, and other** community members. When we asked about referrals from 2-1-1 and the Alzheimer’s Association, we were told that referrals from 2-1-1 were rare, a response consistent with what we were told by 2-1-1 management. Among the information and referral specialists we spoke with, most reported that they never or rarely **receive referrals from the Alzheimer’s Association, but that does not preclude referrals from the Alzheimer’s Association without** the specialists knowing the source. The specialists we spoke with **all said they refer people to the Alzheimer’s Association.**

## Alzheimer’s Association

We interviewed an Alzheimer’s Association care navigator based in Meridian who handles calls for the entire state during office hours. We also interviewed a care consultant with the 24/7 Helpline who assists callers from anywhere in the country. When **a person contacts the Alzheimer’s Association through the local**

or 24/7 Helpline, they have access to clinicians with master's degrees and extensive training on Alzheimer's disease.

A person calling the 24/7 Helpline or getting connected with a care navigator in Idaho will receive a service very similar to that described by the information and referral specialists at the AAAs. The priority would be safety, and if there is an immediate concern after learning more, the navigator or clinician would call the police or adult protective services to ensure someone could find out more about the situation in person. After addressing safety, more questions would be asked to assess the situation and determine the best course of action, including whether the person already had a diagnosis. On some of the more difficult cases, a 24/7 Helpline clinician and a care navigator will work jointly to **determine the best course of action. The Alzheimer's Association** reported that it refers people to local AAAs for homemaking, meals, respite, or adult protective services.

### No system-wide plan for cross referrals

2-1-1 does not act as the centralized, statewide portal the 2013 state plan envisioned. Idahoans get connected with dementia services through a variety of sources. Among the three portals we presented the case study to, each has their own special area of knowledge. Rather than trying to direct everyone to one portal, it may be best to strengthen coordination among information and referral resources that are already available so no matter where someone starts, they get to the right place.

**The Idaho Alzheimer's Planning Group used to help train 2-1-1** staff on dementia services, but efforts dwindled with several **management and software changes. The Alzheimer's Association** and some AAAs have trained each other on their services at various points, but the state does not have a comprehensive plan for dementia partners to connect with each other.

Staff we spoke with reported inconsistent perceptions about the frequency and reasons for one portal to make referrals to another portal. These inconsistencies could be based on the particular experiences of the staff we interviewed, the absence of practices for tracking referral sources, and information and referral specialists not being aware when an outside agency such as the **Alzheimer's Association makes direct referrals to adult protective services.**



# Short-term grants

The Department of Health and Welfare and the Commission on Aging have pursued short-term federal grants to improve services for older adults and caregivers. The main competitive grants affecting Idahoans with dementia are listed below. The area agencies on aging (AAAs) and public health districts are independent organizations that often pursue other grant funding for services in their region.

## Dementia-specific grants

### Dementia capable

Funding period: August 1, 2017–July 31, 2021

The Commission on Aging pursued funding to improve dementia training and access to respite services. Grant activities include the development of online dementia training modules for caregivers, dementia training for information and referral staff at AAAs, and a consumer-directed respite service pilot project in southwest Idaho.

## Other grants impacting Idahoans with dementia

### Family navigation pilot

Funding period: May 15, 2020–February 14, 2022

**The Center for the Study of Aging at Boise State University's College of Health Sciences and the Department of Health and Welfare's Division of Medicaid are working together on a pilot project to assess needs of family caregivers and help them navigate available assistance. Grant activities include program outreach, developing a caregiver assessment tool, and improving information resources.**

## **Adult protective services expansion**

Funding period: September 1, 2018–August 31, 2021

Under a previous grant the Commission on Aging convened stakeholders to identify gaps in adult protective services. Findings informed grant activities, including the expansion of maltreatment screening tools, case management intervention, and data collection.

## **Lifespan respite**

Funding period: September 1, 2017–August 31, 2021

The Commission on Aging expanded respite services to family caregivers with stakeholder input from the Idaho Lifespan Caregiver Action Plan. Grant activities also include increased coordination of services, training, and information access points.





# Responses to the evaluation



This [report] will be a critical resource as stakeholders come together to continue this important conversation. I look forward to working with the Idaho Legislature on policies and actions needed to address this growing public health issue.

—Brad Little, Governor



Should legislators choose to fund a public health dementia response, our Division of Public Health has the knowledge, skills, and expertise internally to manage the public health crisis of increasing dementias.

—David Jeppesen, Director  
 Department of Health and Welfare



The Commission stands ready to help lead the state into a new era of coordination and efficiencies that best serve the people of Idaho.

—Judy B. Taylor, Director  
 Commission on Aging

**1** I agree with the recommendation that the legislature establish an oversight entity to coordinate and oversee the ongoing efforts to address dementia.  
 —Sage Stoddard, Director  
 Area Agency on Aging of North Idaho

**4** I agree with the recommendation to establish a position to coordinate and facilitate the [dementia] programs.  
 —Suzanne B. McCampbell, Director  
 CSI Office on Aging

**2** I am in support of Idaho requiring a specific number of dementia training hours for professionals providing direct services in acute and long term care facilities.  
 —Kristin Schmidt, Director  
 Area II Agency on Aging

**5** Increasing public awareness of caregiver support services is vital especially for caregivers living in rural communities of Idaho.  
 —Michael Hirschi, Director  
 Area V Agency on Aging

**3** We hope the report prompts an initiative to streamline access for individuals and encourage collaboration between organizations.  
 —Raul Enriquez, Executive Director  
 Southwest Idaho Area Agency on Aging

**6** We are also in great need of Geriatric experts and providers in Idaho who are knowledgeable about how to best respond to behavioral crisis in Alzheimer's and dementia patients.  
 —Morgan Nield, Director  
 Area VI Agency on Aging and Senior Services



BRAD LITTLE  
GOVERNOR

November 25, 2020

Rakesh Mohan, Director  
Office of Performance Evaluations  
954 W. Jefferson St., Ste. 202  
Boise, ID 83720

Dear Director Mohan,

I want to thank you and the Office of Performance Evaluations on your thorough report regarding the State's Response to Alzheimer's Disease and Related Dementias. There is no question that this disease is a growing public health issue impacting many Idahoans.

As the report highlights, the number of Idahoans who will experience Alzheimer's Disease will continue to grow as our state and population increases and ages. The need for a coordinated strategy between public health agencies and policymakers in addressing the issue is apparent. The report also addresses the important nexus between the volume of qualified professionals who can assist with treating dementia and our state's ability to diagnosis and care for its citizens.

Thank you again to you and your team for providing a thorough report. This will be a critical resource as stakeholders come together to continue this important conversation. I look forward to working with the Idaho Legislature on policies and actions needed to address this growing public health issue.

Sincerely,

A handwritten signature in blue ink, appearing to read "Brad Little", is written over a light blue horizontal line.

Brad Little  
Governor





BRAD LITTLE- Governor  
DAVE JEPPESEN - Director

# IDAHO DEPARTMENT OF HEALTH & WELFARE

ADMINISTRATIVE PROCEDURES SECTION  
Division of Operational Services  
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P.O. Box 83720  
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November 17, 2020

Rakesh Mohan, Director  
Office of Performance Evaluation  
954 West Jefferson  
Boise, ID 93720

Dear Director Mohan;

Please accept this letter as my formal response to your final report on “Idaho’s Response to Alzheimer’s Disease and Related Dementias” dated November 6, 2020. I always appreciate your thorough and unbiased assessment of our programs. Your report gives me valuable insight and outlines the opportunities we have to improve our programs and services.

I agree with your recommendation that **“Idaho’s dementia response needs a system-wide oversight entity.”** If the legislature wishes to approach a solution for this recommendation, then it is important that the assigned entity be given the authority and responsibility to perform this oversight, and it also must be provided the resources to carry out this important work.

The state already has a model for how a statutorily mandated oversight entity operates. For example, DHW is designated in statute as the state mental health authority and the state substance use disorder authority, which is collectively referred to as the state behavioral health authority. To illustrate this example, the state behavioral health authority is responsible for overseeing Idaho’s behavioral health system of care through a collaborative process.

This model of a statutorily mandated oversight entity would work well to provide Idaho with a system-wide oversight entity to better support Idahoans with Alzheimer’s and dementia.

Though the report stated that **“Idaho does not have a public health response to dementia like it does for other chronic diseases. Behavioral and environmental changes can reduce the risk of dementia.”**; it is important to recognize that DHW does not have funding for a targeted dementia program. While the Division of Public Health (DPH) receives federal grant funding through the Centers for Disease Control and Prevention (CDC) for chronic diseases such as

diabetes, heart disease and stroke, federal funding opportunities for Alzheimer's disease and related dementias are limited. In May 2020, DPH did apply to the CDC for a *Building Our Largest Dementia* (BOLD) infrastructure for Alzheimer's Act funding. Idaho did not receive the funding. Even with the lack of funding for a larger response, existing chronic disease and disease prevention programs continue to integrate brain health messaging.

I agree with the report's conclusion that **"A well-coordinated state dementia program could help primary care providers, caregivers, and the public understand the importance of risk reduction, early detection, and available resources"** and that **"the state should dedicate a position to drive dementia efforts."** Should legislators choose to fund a public health dementia response, our Division of Public Health has the knowledge, skills, and expertise internally to manage the public health crisis of increasing dementias. Public health coordinates with many of the partners and stakeholders identified in the report and would be the appropriate division to house a dedicated staff member.

The report also stated that **"stakeholders reported that Idahoans with dementia have trouble finding residential care placement."** I agree with this finding, particularly as it relates to Idahoans with dementia who are Medicaid recipients. Many of the new licenses for assisted living facilities issued in the past two years have included memory care beds; however, many of the facilities operating those new memory care beds accept Medicaid on a very limited basis. Also, Idahoans with dementia who also have difficult behaviors that put themselves and others at risk of harm continue to face challenges in securing appropriate residential care placement.

Your report also found that **"without sufficient data, we cannot determine the extent to which Idahoans with dementia can access appropriate residential care."** Medicaid will be able to help in the near future with additional data collected because of changes to billing requirements. We will reach out to OPE when the data is available.

Your report determined that **"most Idahoans with dementia who rely on Medicaid live in an assisted living or nursing facility."** I agree with the report's conclusion that those with dementia are more likely to live in an assisted living facility or nursing facility, and that there may be opportunities to serve these individuals in their homes.

To encourage the use of this path of treatment, Medicaid requested and received additional funding in 2018 for residential habilitation providers, including those who serve elderly Medicaid participants who may need these in-home services due to dementia. DHW has seen growth in use of this service since those increases were implemented for the elderly population. We have also actively pursued federal *Money Follows the Person* grant opportunities that allow us to assist people living in nursing facilities to transition to lower levels of care in their communities. While neither of these efforts have been specifically targeted toward people suffering from dementia, they are supportive of providing residential options for those individuals in a more general sense.

In addition, our recent managed care expansion for Idahoans eligible for both Medicare and Medicaid focuses on care management with the goal of serving more members in their homes rather than a congregate or institutional setting.



Related to the report's finding that **"Medicaid likely does not accurately reimburse assisted living facilities for time needed to care for residents with dementia."** We recognize the challenges associated with serving this population in assisted living settings and have recently worked with the Idaho Health Care Association (IHCA) to identify potential improvements to the assessment instrument to address these concerns. To implement these improvements, we will need legislative financial support for both provider rates increases (T&B budget) and additional department staff (personnel budget) and contractors (operating budget).

With respect to comments regarding Medicaid's approach to behavioral care units (BCU), we are in active conversations with the IHCA and their membership regarding how to adjust BCU requirements to support better statewide availability of these residential placements. Medicaid also has implemented a quality payment program to reward providers who demonstrate higher quality care. It may be helpful to consider future measures that advance our goal of improving memory care for Idaho's older adults with Medicaid coverage.

I agree with your finding that **"Idaho has lower dementia training requirements for residential care staff than many neighboring states."** Additional training would help direct care staff more effectively care for Idahoans with dementia. Since imposing additional training requirements will increase operating costs for residential care operators, Medicaid providers may be resistant to new requirements without consideration of increases in Medicaid reimbursement.

Finally, a few thoughts about crisis care for those with dementia/Alzheimer's. Within DHW, the Division of Behavioral Health operates two systems that have potential for involvement, as outlined in the report: the involuntary mental health system and the crisis response system. If the legislature would like to expand the responsibility and authority of DHW to manage a dementia/Alzheimer's crisis response and involuntary health system, additional resources will be needed. If the solution the legislature selects is to enact statute to provide for a dementia / Alzheimer's commitment process, the department will need resources and time to develop, build and operate a facility capable of providing these services.

DHW supports your report and appreciates your findings that help us continue to improve our services and programs for Idahoans. We are committed to improving the experiences of those we serve.

Sincerely,



DAVE JEPPESEN  
Director



## Idaho Commission on Aging

Brad Little, Governor

Judy B. Taylor, Director

November 10, 2020

Rakesh Mohan  
Office of Performance Evaluations  
EMAILED

Dear Rakesh Mohan,

On behalf of the Commission on Aging and the Aging Network, I would like to thank and commend the Office of Performance Management for this fair and timely report. The Commission is proud of its efforts to support people living with Alzheimer's and related dementias, and welcome the opportunity to further lead, participate and collaborate on statewide efforts.

At its core, the Commission on Aging is a planning organization, focused on enabling older and disabled Idahoans to live in the community for as long as possible. Using evidence-based methodology and statewide outreach we continually identify and execute program improvements and uncover gaps in services. We have recently ended a planning cycle, culminating with a new 4-year state plan accepted by the Administration for Community Living September 4, 2020.

Many of the gaps identified in the OPE report have already been addressed in our accepted State plan. In 2021 the 6 regional Area Agencies on Aging will use ICOA's State plan to create their own local plans. If any Idahoan would like to participate in local planning to meet the needs of people living with Alzheimer's and related dementias and their caregivers, you can use our website to locate the contact information of your local Area Agency on Aging.

We also invite you to access our website at [www.aging.idaho.gov](http://www.aging.idaho.gov) for up to date information, resources, and education.

With trained and supported caregivers, and appropriate home and community-based services, we know people living with Alzheimer's can continue to have quality of life, surrounded by their most familiar and comfortable environment. The Commission stands ready to help lead the state into a new era of coordination and efficiencies that best serve the people of Idaho.

Respectfully,

A handwritten signature in black ink that reads "Judy B. Taylor".

Judy Bicknell Taylor MSN, RN  
Director, Idaho Commission on Aging





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November 18, 2020

Rakesh Mohan, Director  
Office of Performance Evaluations  
Idaho Legislature

Dear Mr. Mohan

I am the director of the Area Agency on Aging of North Idaho (AAANI) which serves the 5 northern counties of Idaho. This area includes the counties of Benewah, Bonner, Boundary, Shoshone, and Kootenai.

Thank you so much for the opportunity to review and respond to the “State Response to Alzheimer’s Disease and Related Dementias” report. This is such an important topic for the people of Idaho, and particularly the people we serve on a daily basis. As discussed in your report, there is approximately 27,000 Idahoans over the age of 65 identified having Alzheimer’s disease.

This is an excellent report and the research for this report was very thorough and well done. You and your staff are to be commended for the professional way in which interviews were conducted throughout the state. Thank you for including myself and the staff of AAANI in this process.

I agree with the recommendation that the legislature establish an oversight entity to coordinate and oversee the ongoing efforts to address dementia. The projected growth of 22% in the number of cases of Alzheimer Disease over the next five years supports this recommendation. I also agree with establishing a position to coordinate and facilitate the programs and requirement of a specific number of dementia training hours for assisted living facility staff, both initially and ongoing. There is a great need to coordinate activities between all the various entities in the State which are trying to work with this devastating disease.

The State of Idaho could benefit from having increased number of providers who specialize in Alzheimer and dementia care. I support of the recruitment of additional medical professionals to provide diagnostic and treatment for these patients. I also agree with adding training requirements for those caring for patients with Alzheimer’s and other dementias in acute and long-term care settings.

Thank you again for this opportunity to work with you on this report!

Sincerely

Sage Stoddard  
Director Area Agency on Aging of North Idaho



**Community Action Partnership**

124 New 6<sup>th</sup> Street  
Lewiston, ID 83501  
(208) 746.3351  
1.800.326.4843

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November 16, 2020

Rakesh Mohan, Director  
Office of Performance Evaluations  
Idaho Legislature

Dear Mr. Mohan,

I am the Area Agency on Agency (AAA) Director of Area II serving North Central Idaho in the following 5 counties: Latah, Nez Perce, Clearwater, Lewis, and Idaho.

I want to thank you for the opportunity to review and respond to the "State Response to Alzheimer's and Related Dementias" report. The report was thorough and insightful, and such an important topic for the people of Idaho, particularly the seniors we serve. Thank you, too, for the review of surrounding states and the comparisons made in the way services are provided. There is so much we can learn from others who have engaged in similar work and can share their successes and their challenges.

I am in support of Idaho requiring a specific number of dementia training hours for professionals providing direct services in acute and long term care facilities and I agree that the State of Idaho could benefit from having an increased number of providers who specialize in Alzheimer's and dementia care.

Again, thank you and congratulations to you and your team on an exceptional report!

Respectfully,

*Kristin Schmidt*  
Area II Agency on Aging Director



November 16, 2020

To whomever it may concern,

We appreciated the opportunity to participate and provide input on the Office Performance Evaluation's State Response to Alzheimer's Disease and Related Dementia. The Southwest Idaho Area Agency on Aging (SWIA3) and its staff support the information provided in the report. We believe the report adequately describes the barriers experienced by individuals with dementia and their families.

We hope the report prompts an initiative to streamline access for individuals and encourage collaboration between organizations. We are willing and open to start collaborating with the many organizations listed in this report.

Sincerely,

A handwritten signature in black ink that reads "Raul Enriquez". The signature is written in a cursive, flowing style.

Raul Enriquez,  
Executive Director



November 12, 2020

Rakesh Mohan, Director  
Office of Performance Evaluations  
Idaho Legislature

Dear Mr. Mohan,

I am the director of the CSI Office on Aging which is the Area Agency on Aging for the eight counties of South-Central Idaho. This region includes Blaine, Camas, Cassia, Gooding, Jerome, Lincoln, Minidoka and Twin Falls Counties.

Thank you so much for this opportunity to review and respond to the "State Response to Alzheimer's Disease and Related Dementias" report. This is such an important topic for the people of Idaho, and particularly the seniors whom we serve. As discussed in your report, the projected growth of 22% in the number of cases of Alzheimer's Disease over the next five years points to the urgency we need to give to the management of this disease within the State of Idaho.

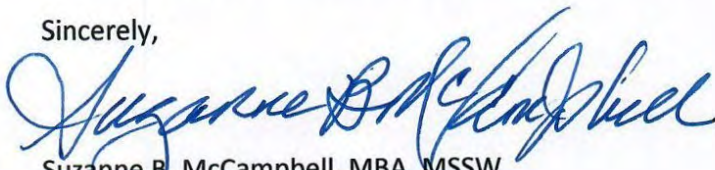
This is an excellent report! I thought that the research for this report was very thorough and well done. I particularly appreciated the review of the surrounding states and the comparisons made in the provision of services. You and your staff are to be commended for the professional way in which interviews were conducted. I am honored that I had the opportunity to give input into this process.

I agree with the recommendations that the legislature establish an oversight entity to coordinate and oversee the ongoing efforts to address dementia. I also agree with the recommendation to establish a position to coordinate and facilitate the programs. There is a great need to coordinate activities between all the various entities in the State which are trying to work with this devastating disease.

I am also strongly in support of the recruitment of additional medical professionals to provide diagnostic and treatment for these patients. I also agree with adding training requirements for those caring for patients with Alzheimer's and other dementias in acute and long-term care settings and should be extended to senior center workers and caregivers at home.

Thank you again for this opportunity to work with you on this report!

Sincerely,

  
Suzanne B. McCampbell, MBA, MSSW  
Director, CSI Office on Aging





*Building Bridges to Communities*

P.O Box 6079 • Pocatello, ID 83205-6079

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*for the Advancement*  
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*Pocatello Central*

*Labor Council*

*The Shoshone*

*Bannock Tribes*

*Economic & Community*  
*Development Division*

*Area Agency on Aging*

November 16, 2020

Rakesh Mohan, Director  
Office of Performance Evaluations  
Idaho Legislature

Dear Mr. Mohan,

My name is Mike Hirschi and I am the director of the Area V Agency on Aging of Southeast Idaho. Our planning and service area consists of the following counties: Bannock, Bear Lake, Bingham, Caribou, Franklin, Oneida and Power. I want to thank you for the opportunity to review and respond to the 'State Response to Alzheimer's Disease and Related Dementias' report for Idaho.

I want to commend you and your staff of the Office of Performance Evaluations for the comprehensive evaluation and report on the progress of the 'Idaho State Plan for Alzheimer's Disease and Related Dementias.' This report identified approximately 27,000 Idahoans over 65 years old have Alzheimer's disease and that figure is expected to grow 22 percent in the next five years. The considerations identified in Chapter 7 of the report are a roadmap the State of Idaho desperately needs to address dementia as a growing public health concern.

I have worked with Idahoans living with Alzheimer's disease and Dementia and their caregivers for over 25 years and personally have had a family member with dementia. I wholeheartedly agree with the recommendation that the Legislature establish a system-wide oversight entity to build on agency efforts, improve collaboration among dementia partners, and ensure ongoing accountability for outcomes. Furthermore, I support the recommendation to establish a position to coordinate and facilitate the programs. The steps identified in Chapter 7 to further develop Idaho's dementia response clearly explain the strategies that should be addressed as our state moves forward in addressing this public health concern.

I strongly support the specific steps identified for family caregivers. This report noted the Alzheimer's Association analysis of Centers for Disease Control and Prevention and AARP survey findings that in 2019, 87,000 caregivers of Idahoans with dementia provided 99 million hours of unpaid care. Increasing public awareness of caregiver support services is vital especially for caregivers living in the rural communities of Idaho. A dementia roadmap as suggested in the report would be a valuable asset to share with all of our community partners to show a coordinated effort of support to those Idahoans living with dementia and their caregivers.

Page 2  
Mr. Rakesh Mohan  
November 16, 2020

The most valuable gem in Idaho is our people. Working together we could ultimately be the source that other states want to emulate when it comes to providing the infrastructure to making improvements for Idahoans with dementia and their families. Thank you for the opportunity to work with you and your team on this report.

Sincerely,

A handwritten signature in dark ink, appearing to read "Michael Hirschi". The signature is fluid and cursive, with a long horizontal stroke at the end.

Michael Hirschi  
Area V Agency on Aging Director



## EASTERN IDAHO COMMUNITY ACTION PARTNERSHIP

935 E. Lincoln Rd  
P.O. Box 51098  
Idaho Falls, Idaho 83405  
(208) 522-5391  
1-800-632-4813

Award for Excellence in Community Action

November 9, 2020

Dear Office of Performance Evaluations Idaho Legislature,

My name is Morgan Nield, and I am the Area Agency on Aging (AAA) and Senior Services Director for Area VI in Idaho Falls. Our service area includes the following 9 counties in Eastern Idaho: Bonneville, Butte, Clark, Custer, Fremont, Jefferson, Lemhi, Madison, and Teton. It is my pleasure to provide this Formal Agency Response to Report in regard to the report's findings, conclusions, and recommendations on Idaho's response to Alzheimer's disease and related dementias.

First, I would like to commend Office of Performance Evaluations on the excellent report. Their research was very thorough, and I appreciated the way that they outlined how neighboring states have structured a more comprehensive system for dementia services. I also respected the feedback that OPE gathered from a variety of state and local stakeholders and I enjoyed being involved in the process as a local "boots on the ground" stakeholder.

There are several entities at both the state and local level (including the AAA's) that are passionate about serving those with Alzheimer's and dementia, but we often operate in our own silos. I strongly agree with the policy considerations outlined on page 72 of the report: 1) Idaho's dementia response needs a system-wide oversight entity and 2) The state should dedicate a position to drive dementia efforts.

In addition, I am in full support of Idaho requiring a specific number of dementia training hours for assisted living facility staff, both initially and ongoing.

Furthermore, I completely agree that the State of Idaho could benefit from having increased number of providers who specialize in Alzheimer's and dementia care. We are also in great need of Geriatric experts and providers in Idaho who are knowledgeable about how to best respond to behavioral crisis in Alzheimer's and dementia patients.

I am thankful for the opportunity to have been involved in this process. This report outlines some very promising steps that Idaho can take to improve the supports and services that are available for individuals with Alzheimer's and dementia.

Sincerely,

Morgan Nield, BS, CCAP  
Area VI Agency on Aging and Senior Services Director







